

PREVENT BLINDNESS POLICY AND ADVOCACY OVERVIEW: Advocating for a Lifetime of Healthy Vision









Message from Prevent Blindness President and CEO Jeff Todd

Since 1908, Prevent Blindness has been a leader in advocating for vision and eye health for Americans of all ages, backgrounds, and circumstances. Today more than ever we are seeing trends in population growth and demographic shifts that collide with new innovative sight-saving treatments, medical and public health research, and methods of accessing care such as community interventions and telehealth. Our mission to protect and enhance access to vision and eye care through advocacy at the federal and state levels has only become more vital.

During 2019 and 2020, Prevent Blindness built on our foundation for ongoing advocacy as we urged federal policymakers to make vision and eye health a national public health priority. We increased Congress's understanding of the need to invest in children's vision and eye health and strengthen our national vision and eye health surveillance. Our advocacy during a once-in-a-century global pandemic focused on continuity of care for patients who need vision and eye care services and treatments. New and reinforced lessons were learned about how gaps in access to eye care across populations must lead future advocacy efforts. As the nation grappled with issues of social justice, we were reminded that we can't have a just society without equity in healthcare. Our work continues to underscore the need to ensure that vision and eye health be a part ofand not a supplement to-national conversations on access, equity, and outcomes.

Above all, we elevated patient voices to the halls of Congress to tell their stories about living with vision loss and eye disease and fight for policies that protect access to sight-saving care. Changing policymakers' minds about vision and eye care is a mountainous challenge that can be achieved only with the voice of the patient leading demands for policies that prevent blindness and preserve sight. While we can and should occasionally stop and celebrate our many advances, the reality remains that 93 million Americans are at risk for vision loss. Our task is great, but momentum to protect the gift of sight is on our side.

I am honored to stand alongside my colleagues (staff and volunteers across the country) at an organization whose ever-evolving legacy ensures that Americans can live, work, play, and engage with the world around them, supported by a public health system that maximizes the vision and eye health of all. I encourage you to join our efforts in 2021-2022 (and beyond!). Be a Visionary for Sight!

"If not us, then who? If not now, then when?"

- Former Congressman John E. Lewis (D-GA) and Member of the Congressional Vision Caucus Message from Prevent Blindness Chairman of the Board of Directors, M. Kathleen Murphy, RN, DNP and Public Health and Policy Committee Chairman, Mitchell V. Brinks, MD, MPH

Advocacy at Prevent Blindness has never come at a more critical time. Policymakers in Washington lead a nation that is more divided than ever; yet, the need to come together on issues that are important to constituents and patients is ever present. Vision loss and eye disease impacts **everyone** – no matter your personal values, racial or ethnic background, political leanings, or socioeconomic circumstances. We all share the same wish: to live fulfilling, productive lives with clear, healthy eyesight. Prevent Blindness will continue to strive for equitable access to vision and eye care for all Americans.

On behalf of Prevent Blindness's Board of Directors, we urge our lawmakers and administrators across the federal government to work together on policies that help Americans prevent avoidable vision loss and achieve optimal vision and eye health, regardless of their background or circumstances. We thank the leaders of the Congressional Vision Caucus—Rep. David Price (D-NC), Rep. Steve Stivers (R-OH), and Rep. Gus Bilirakis (R-FL) for their continued efforts to lead a national dialogue on vision issues in Congress. We applaud the many advocates who have lent their voices to the cause of protecting our national vision and eye health, and we encourage you to continue to using your voice and experiences to affect change in Washington, DC on this very important matter.

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OVERVIEW OF PREVENT BLINDNESS ADVOCACY

Prevent Blindness is dedicated to preventing blindness and preserving sight by advancing through public policy the full spectrum of vision care and eye health for people of all ages, backgrounds, and circumstances. As a nonpartisan organization, we advocate for policies that improve the nation's vision and eye health by fostering access to vision and eye care services and treatments, enhancing state and community capacities, reinforcing messages of early detection and disease prevention, creating and sustaining patient support networks and services, elevating systems of care, and fostering innovative research.

Prevent Blindness advocacy benefits from strong relationships with organizations across the patient advocacy and public health community to advance shared policy goals that may not directly affect vision and eye health but nonetheless have an impact. Through our state affiliate organizations and programs located in

Georgia, Illinois, Iowa, Massachusetts, North Carolina, Ohio, Texas, and Wisconsin, we bring awareness to lawmakers on vision and eye health issues facing their constituents and encourage increased federal investments to vision and eye health programs for working and aging adults and children at the federal level.

Every two years, the dynamics of policy and politics shift in Washington, DC with an election that ushers in new leadership in Congress and, sometimes, the Administration. In order to ensure the appropriateness of these recommendations and identify new opportunities for partnership with other organizations and relationships on Capitol Hill, Prevent Blindness will assess our policy agenda every two years. As we reflect on the advocacy from the prior two years, Prevent Blindness reinforces the need to elevate vision and eye health into existing approaches on public health, access, and health equity.



EYES ON CAPITOL HILL: CONGRESSIONAL ADVOCACY DAY

Since 2006, advocates from across the country have visited Washington, DC every year to meet with legislators on Capitol Hill in our signature advocacy event and fly-in- Eyes on Capitol Hill. This event provides constituents—from patients who are living with vision loss or eye disease, eye care practitioners who have treated patients, researchers who understand trends in innovative eye care treatment, technology, or public health, or community leaders in expanding access to vision and eye care in their communities—an opportunity to inform Congress about the challenges Americans face accessing vision and eye care. Our advocates reinforce the importance of prevention, early intervention in order to detect and prevent eye diseases from progressing by connecting patients to care, and informing Congress on the federal programs that help promote our nation's vision and eye health.

Looking ahead, the 2021 Eyes on Capitol Hill will be the first in Prevent Blindness history to be conducted virtually due to the ongoing COVID-19 pandemic. However, since vision and eye health care continue to be in accessible to millions of Americans, our work in advocating directly with Congress continues even through the pandemic.



Advocates from the 2019 Eyes on Capitol Hill Congressional Fly-in Event, July 2019

2019

In coordination with our annual "Focus on Eye Health" National Summit, Prevent Blindness hosted 57 advocates who met with over 65 House and Senate offices—including 14 scheduled meetings with Members of Congress—to discuss vision and eye health. Our advocates thanked Members of Congress for doubling the Vision Health Initiative (VHI) at the Centers for Disease Control and Prevention (CDC) budget from \$1 million to \$2 million and retaining the Glaucoma program's funding level at \$4 million.

Advocates asked the Senate to appropriate \$5 million to the CDC's VHI, maintain the CDC's Glaucoma program funding at \$4 million, and increase National Eye Institute funding to \$850 million. As well, advocates educated Members of Congress on the work occurring in their communities to bring children to eye care, close gaps in access to vision care for all ages, sand promote early detection and prevention of potentially blinding conditions and eye diseases across the lifetime. The day was capped with a reception hosted by the Congressional Vision Caucus, and attended by Caucus co-chairs Rep. David Price (D-NC) and Rep. Steve Stivers (R-OH) who each delivered remarks to attendees.



Advocates from Prevent Blindness North Carolina meet with Congressional Vision Caucus Co-Chair, Congressman David Price (D-NC)

2020

In a departure from recent years, Prevent Blindness transitioned our Eyes on Capitol Hill advocacy day from summer to February to accommodate the Congressional calendar and align our advocacy agenda with the appropriations schedule. The fast-turnaround in planning and logistics meant that fewer advocates could attend; however, despite the lower number of advocates from previous years—only 15 in 2020 over 55 meetings were held with Members of Congress to request \$5 million to improve the **CDC's Vision and Eye Health surveillance efforts** and to maintain CDC's glaucoma line at \$4 million. We also used the time to inform lawmakers of the need to invest in children's vision and eye health.

Additional Information: 2020 Eyes on Capitol Hill Fact Sheet; Eyes on Capitol Hill Event Page; Be an Advocate for Vision





Prevent Blindness staff and Prevent Blindness Iowa advocates with Senator Joni Ernst (R-IA), February 2020



Prevent Blindness Ohio advocates with **Congressional Vision Caucus Co-Chair** Congressman Steve Stivers (R-OH), February 2020

CONGRESSIONAL VISION CAUCUS

The Congressional Vision Caucus (CVC) is a bipartisan, bicameral coalition of Members of the U.S. House of Representatives and the U.S. Senate who are dedicated to strengthening public policy addressing vision-related problems and disabilities. Prevent Blindness played a major role in forming the Caucus in 2010, and we work closely with its Members to advance legislation and inform Congress of policy impacts to vision and eye health.

The CVC is currently co-chaired by Congressmen Steve Stivers (R-OH), Gus Bilirakis (R-FL), and David Price (D-NC). Prevent Blindness encourages Members of the 117th Congress to join their colleagues on the CVC to promote and strengthen vision and eye health policy and protect access to sight-saving vision and eye care.



Rep. David Price (D-NC)

CO-CHAIRS



Rep. Steve Stivers (R-OH)



Rep. Gus Bilirakis (R-FL)

MEMBERS 116th CONGRESS

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Rep. Jared Huffman (CA)

Rep. Collin Peterson (MN)

Rep. Sanford Bishop (GA)

Rep. Sheila Jackson-Lee (TX)

Del. Stacey Plaskett (USVI)

Sen. Marsha Blackburn (TN)

Rep. Frank Lucas (OK)

Rep. Mark Pocan (WI)

Sen. John Boozman (AR)

Rep. Bill Johnson (OH)

Rep. Bobby L. Rush (IL)

Sen. Sherrod Brown (OH)

Rep. Hank Johnson (GA)

Rep. Tim Ryan (OH)

Rep. G.K. Butterfield (NC)

Sen. Doug Jones (AL)

Rep. Jan Schakowsky (IL)

Rep. Andre Carson (IN)

Rep. David Joyce (OH)

Rep. David Scott (GA)

Rep. Steve Chabot (OH)

Rep. Marcy Kaptur (OH)

Rep. Terri Sewell (AL)

Rep. Gerry Connolly (VA)

Rep. Joe Kennedy (MA)

Rep. Mike Simpson (ID)

Rep. Jim Cooper (TN)

Rep. Ron Kind (WI)

Rep. Chris Smith (NJ)

Rep. Rick Crawford (AR)

Rep. Bob Latta (OH)

Rep. Michael Turner (OH)

Rep. Elijah E. Cummings (MD)

Rep. Barbara Lee (CA)

Sen. Chris VanHollen (MD)

Rep. Danny K. Davis (IL)

Rep. John Lewis (GA)

Rep. John Yarmuth (KY)

Rep. Peter DeFazio (OR)

Rep. Daniel Lipinski (IL)

Rep. Lloyd Doggett (TX)

Rep. Dave Loebsack (IA)

Rep. Eliot Engel (NY)

Rep. Nita Lowey (NY)

Rep. Anna Eshoo (CA)

Rep. Carolyn Maloney (NY)

Rep Bob Gibbs (OH)

Rep. Frank Pallone (NJ)

Rep. Raul Grijalva (AZ)

Rep. Bill Pascrell (NJ)

Rep. Brian Higgins (NY)

Rep. Donald Payne (NJ)

COALITIONS AND PARTNERS IN ADVOCACY



Prevent Blindness collaborates with patient advocacy groups, health care policy thought leaders, provider and professional organizations, industry and trade associations, disability advocates, and others where necessary on areas that have a broader reach than vision and eye health but may nevertheless pose a potential benefit or harm to vision and eye health without the right policy solutions. Coordinating efforts with organizations through opportunities such as sign-on letters to Congress or the Administration, public comment in rulemaking processes, statements of principle and policy objectives, press statements, bill endorsements, issue advocacy through social media channels, and issue briefs or fact sheets amplifies our own advocacy on behalf of patients with vision loss and eye disease, helps to breaks down siloes that separate vision and eye health from broad health policy goals, and helps us achieve advocacy successes that would be too difficult to take on as a singular effort.

Much of our advocacy work is accomplished through coalitions that are either informal, ad hoc or issue-based, or formalized through membership and governance structures. In 2019 and 2020, Prevent Blindness maintained our membership with groups such as the National Health Council, Coalition for Health Funding, Children's Budget Coalition, Part B Access for Seniors and Physicians (ASP) Coalition, the Patient Access Network (PAN) Foundation, and several others. Within the vision and eye health community, Prevent Blindness has partnered with our colleagues in vision through such groups as the National Alliance for Eye and Vision Research, ITEM Coalition, Vision Health Advocacy Coalition, and Vision 2020 USA to achieve mutual policy goals respective to vision and eye health.

Through our advocacy partnerships, we have:

- Sustained and, in some cases increased, funding for programs at the Centers for Disease Control and Prevention, the National Institutes of Health, and the Health Resources and Services Administration.
- · Secured new investments to modernize our nation's public health data infrastructure, and
- Reauthorized programs on services for older Americans, schoolbased health, diabetes prevention, and health quality.

For more information on our coalition partnerships, visit our Coalition Letters and Statements page.

ACCESS TO VISION AND EYE HEALTH CARE

Access to vision and eye care is a multi-faceted issue that requires diverse approaches to be properly addressed. For patients, access to care may depend on the ability to acquire transportation or the technology needed to access in-network care, including treatment, therapy, or rehabilitative services. A patient's health literacy, culture, and socioeconomic status can also impact access to care and ability to prioritize vision and eye health among other costly and burdensome conditions.

At the community level, barriers in access to care could include lack of public awareness about risk factors for eye disease like family history or behaviors such as smoking, health promotion efforts that exclude vision and eye health information, or public policies that are misaligned with goals for a broader population. Federal policies surrounding cost, provider reimbursement, and network design should be patient-centered and focus on bringing care to a patient's community and create access where possible, as well as address access and equity factors that can facilitate and encourage patients to seek care.

Telehealth and Telemedicine

Telehealth provides the opportunity to expand access to eye care in communities where it is unlikely that the appropriate and necessary eye care provider(s) will be physically and adequately present to address the needs of individuals and a population. Particularly during the COVID-19 pandemic, telehealth has unquestionably become an invaluable way for patients to receive care in a safe and socially distant manner. The rapid expansion of telehealth (which has in many ways become a great American experiment in health care delivery) warrants new ways of thinking about how telehealth and telemedicine can complement vision and eye care through disease prevention and health promotion, early detection and risk assessment, care coordination, and disease monitoring. Further considerations include how

Telehealth can be utilized to achieve population health goals like closing gaps in access, reaching underserved and rural areas, community care, integration of vision and eye care into other health approaches, and fostering patient-centered care.

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While telehealth cannot fully substitute the benefits of an in-person eye examination, if executed correctly, initial screenings via telemedical technology can be a valuable access point for the detection of possible eye diseases and ultimately help to prevent vision loss. Additionally, telemedicine can enable care coordination, facilitate receipt of a comprehensive vision examination, and allow for disease monitoring in concert with needed and appropriate in-person care. Telehealth, however, should reflect a standard of care so that quality of care provided is not diminished. Telehealth policies should also reflect aspects of health equity (including in broadband capability, health literacy, and language interpretation) and accessibility (including audio-only telehealth for those living with low vision or blindness or who may be unable to afford technology to engage in video visits) so

that telehealth does not become an additional barrier to eye care or raise additional disparities in access.

Policy Outlook and Positioning:

In 2020, a rush of Congressional and Administrative action relaxed regulations governing the use of telehealth and telemedicine across both public and private plans to ensure continuity of care at the onset and through the duration of the COVID-19 pandemic. The aim of these regulations ensured that providers would be paid the same for telehealth visits as they would for inperson care by waiving certain policies like geographic or "originating site" restrictions or loosening criteria on what kind of services could be provided using telehealth. Congress also included additional flexibilities for rural health clinics and federally qualified health centers to offer telehealth services in emergency legislation to address the COVID-19 pandemic.

Several bills introduced during the 116th Congress focused on extending telehealth flexibilities permanently in light of the pandemic; however, most bills

As policy efforts around telehealth move ahead and lawmakers consider its role in postpandemic virtual care, **Prevent Blindness will** review legislation and **Administrative actions** and advise on policy in order to ensure that the right balance between in-person, clinical care and telehealth is implemented as appropriate for the eye care patient.

are narrow in scope to certain specialties like behavioral health or expanding sites of care under the "originating sites" statutory definition. **Prevent Blindness** endorsed S. 2020, the Screenings for Eye Evaluation, Monitoring, Observation, Review, and Examination (SEE More) Act, which was introduced in 2019 and would remove originating site restrictions for services that would detect chronic eye disease. Some legislation promotes the use of remote patient monitoring for chronic conditions.

The Biden Administration is expected to embrace policies created under the Obama Administration and build on the Trump Administration's efforts to free up patient data and expand telehealth and virtual health, and seek ways to improve access and equity through telehealth. The Biden Administration is also expected to propose investments to build new health clinics and deploy telehealth in rural America. While narrow Democratic majorities in Congress may limit large-scale legislation, there are areas ripe for bipartisan cooperation and for government and industry collaboration in the area of virtual health. The Administration has a wide latitude on what they can do in the virtual health space, including setting reimbursement levels and encouraging or discouraging practices, and may also focus on changes that make health data and technology work through digital platforms that promote patient information on health records.

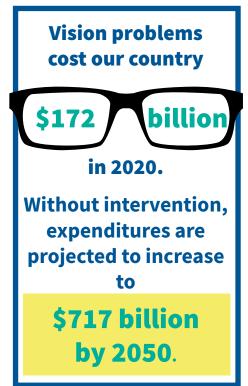
Sustaining telehealth as an avenue to vision and eye care will require working in concert with the general health community, as nearly every stakeholder and area of care will need to consider how telehealth can enhance care processes while still maintaining quality of care, mitigating overutilization, and promoting evidencebased practices. It will be important for policy efforts to consider how to mitigate inequities in telemedical access due to disparities in technology accessibility and affordability so that telehealth does not become another way to perpetuate health inequities. As policy efforts around telehealth move ahead and lawmakers consider its role in post-pandemic virtual care, Prevent Blindness will review legislation and Administrative actions and advise on policy in order to ensure that the right balance between in-person, clinical care and telehealth is implemented as appropriate for the vision and eye care patient.

Prevent Blindness Advocacy:

Prevent Blindness endorses S. 2020, the SEE More Act

Cost of Care

The rising costs of health care in the United States is a significant and complex policy issue. Cost is often the



primary barrier for patients who seek to access care that can help prevent and treat chronic illness, including blinding eye diseases. The national cost of vision problems, including private and public payments for medical care, long-term care, patients' out-ofpocket costs, direct and indirect costs, and lost productivity and consequential lost tax revenue amounted to \$172

billion in 2020, and is expected to increase to \$274 billion by 2032 just as the final ranks of the baby boomer generation become Medicare-eligible.

According to <u>national forecasts</u>, expenditures on vision problems will reach \$385 billion by 2032 and \$717 billion by 2050. Vision impairment and eye disease often contribute to debilitating, costly, and chronic conditions, including: diabetes, injuries and death related to falling, stroke, depression and social isolation, cognitive decline, lack of mobility, and need for long-term

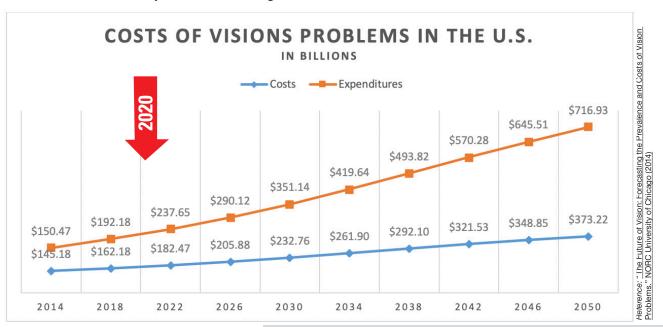
care. In addition, studies have found that patients with vision loss experienced longer hospital stays and higher readmission rates, resulting in \$500 million in excess costs. Nationally, cost of care is driven by a number of vision-related factors, including our aging population as well as the increasing prevalence of chronic diseases.

Policy Outlook and Positioning:

National expenditure on health care is a major theme in policy, particularly because health outcomes are not improving as a result of high spending. Numerous policy proposals include improving quality of care, reducing barriers for market access of generic and biosimilar products, improving transparency of prices to achieve health literacy and consumer engagement, and creating value-based incentives on payers and providers. Prevent Blindness advocates for policies that promote access to health care for patients as well as coverage options that allow patients to prioritize their vision health and eye care as a part of their overall health and well-being. We encourage policymakers to consider vision and eye health as part of overall health and well-being. Prevent Blindness reiterates that vision health is an essential contributor to overall health and well-being, and therefore should be an aspect, not a supplement, of health care coverage.

Prevent Blindness Advocacy:

Prevent Blindness: The Cost of Vision Problems



COVERAGE AND INSURANCE

Insurance, whether through a private or public program, is the primary way most Americans obtain and pay for their health care (including vision and eye health) and treatments. Insurance can help reduce cost-related obstacles and ensure the continuity of care that is vital to monitoring disease progression and avoiding progressive vision loss through early detection and prevention. Unfortunately, a patient's inability to access coverage due to lack of affordable options or plans that do not offer comprehensive care for eye health can make it challenging for a patient to prioritize their vision and eye care needs. Increasingly, plan designs, narrow networks, or step therapy and other utilization management techniques employed in some medical plans may pose additional burdens for patients who need vision and eye care services or treatment.

Medicare and Vision Health

Because many aging Americans rely on Medicare for their health needs, Medicare is a logical opportunity to prevent eye diseases (for example, age-related macular degeneration [AMD]) from progressing to vision loss or impairment. Access to preventive measures such as a comprehensive eye exam (which is suitable to detect disease, determine its state of progression, and provide the most effective treatment) can help older Americans maintain their independence and quality of life while preventing and reducing costs to the patient and the system. Additionally, better integrating vision and eye health into primary care settings or at logical intervention points-such as falls risk assessments before a fall occurs and screenings for modifiable behaviors such as smoking, cognitive decline, and mental and emotional health status—will help close critical gaps in coverage, address health disparities across populations, and contribute to lower Medicare spending on chronic diseases, hospitalization and readmission, injury and rehabilitation from falls, and long-term care.

The "Welcome to Medicare" benefit is a natural access point for comprehensive eye exams to occur as it allows for patients to be referred to specialty care, if needed, and fosters care coordination through a referring provider. The **Annual Wellness** Visit also provides an opportunity for beneficiaries to receive eye care; however, Medicare currently only offers visual acuity screenings in the "Welcome to Medicare" benefit and generally only covers eye exams in order to detect and diagnose eye

99.6% Medicare beneficiaries self-reported having a vision problem such as:

- · needing eyeglasses,
- · having trouble seeing,
- · have a diagnosis of legal blindness,
- · needing a visual assistive device, or
- had cataracts, glaucoma, diabetic retinopathy, or macular degeneration.

2018 Medicare Current Beneficiary Survey and 2016 Medicare Current Beneficiary Survey

disease for patients at risk of developing diseases such as glaucoma and diabetes. Prevent Blindness promotes eye health at every stage of life, including for older Americans, as vision can help achieve broader policy goals around healthy, independent aging.

Policy Outlook and Positioning:

In 2019, the House included H.R. 4665, the Medicare Vision Act of 2019 as an amendment to H.R. 3, the Lower Drug Costs Now Act, which sought to lower the costs of prescription drugs. H.R. 4665 would create a Medicare vision benefit that covers an annual "routine" eye exam and either one pair of eyeglasses, including lenses, or an annual supply of contact lenses. H.R. 3, which also included a Medicare dental and hearing benefits, sought to offset the costs of providing these new benefits by using the savings generated through international price controls implemented on certain, pricey drugs that are covered under the Medicare Part B program. H.R. 3 passed the House in December 2019, but it was not considered in the Senate.

Prevent Blindness issued a statement on H.R. 3, expressing appreciation for Congress's recognition of the need to address vision and eye health in the Medicare program but outlining concerns that the new benefits would come at the expense of sight-saving treatments for progressive eye diseases, such as agerelated macular degeneration. If the 117th Congress resumes consideration of this bill, Prevent Blindness will take the opportunity to inform lawmakers about the need to address the gaps that exist in Medicare vision and eye health coverage, and encourage policies that prioritize vision and eye health treatments, comprehensive eye exams, and integrated preventive care as a part of a way to achieve shared policy goals on lowering costs and improving health outcomes for seniors.

Prevent Blindness Advocacy:

Prevent Blindness Fact Sheet: Medicare Benefits and Your Eyes; Prevent Blindness Statement on Lower Drug **Costs Now Act**

Medicare Coverage of Low Vision Devices and Assistive Technology

Prevent Blindness promotes eye health at every stage of life, including for older Americans, as vision can help achieve broader policy goals around healthy, independent aging. Low vision devices can help those with uncorrectable vision impairment be independent in their activities of daily living. In 2008, the Centers for Medicare and Medicaid Services (CMS) codified a provision to exclude from Medicare coverage for eyeglasses, contact lenses, and low vision aids such as corrective or assistive devices and technologies for

use with low vision conditions that result from genetic conditions, developmental issues, disease, or injury. This "lens exclusion" means that beneficiaries who need these aids must pay for them wholly out of pocket. While Medicare Advantage plans tend to cover some low vision devices and services, the out-of-pocket cost to the beneficiary for these devices may pose an additional barrier to care that could diminish quality of life, make activities of daily living harder to maintain, advance additional vision loss, and increase the likelihood of poor health outcomes associated with vision loss and eye disease.

Policy Outlook and Positioning:

With legislation to create a Medicare vision benefit having passed in the House, there is new interest in addressing the gaps in Medicare coverage. However, as written, H.R. 3 did not include coverage of low vision devices and assistive technology. President Biden indicated during his campaign for president a need to make changes to Medicare coverage to include vision rehabilitation and ensuring technologies are made available; however, expanding Medicare in any way faces significant political headwinds in a closely divided House and Senate over the next 2 years.

Increasingly, Prevent Blindness has been involved in policy planning and discussions with low vision stakeholders such as the Vision Serve Alliance to elevate low vision as a public policy priority. In 2020, Prevent Blindness and several vision and eye health organizations joined the Independence Through Enhancement of Medicare and Medicaid (ITEM) Coalition to advocate for coverage of low vision devices and assistive technologies in Medicare. The ITEM Coalition has advocated to the Administration through the regulatory process governing Medicare reimbursement for medical equipment and supplies to cover low vision devices and assistive technologies for Medicare beneficiaries who need them. Our efforts through the ITEM Coalition may include advocating to the 117th Congress to consider reversing statutory language prohibiting coverage for these devices.

Prevent Blindness also issued comment in support of the Trump Administration's proposal to

fast-track Medicare coverage of new, innovative breakthrough devices in the Medicare program. This new coverage pathway, the Medicare Coverage for Innovative Technology (MCIT) pathway, could potentially create a glidepath for coverage of low vision devices and assistive technologies if it is ultimately implemented under the Biden Administration.

Prevent Blindness Advocacy:

Prevent Blindness Comment on Medicare Coverage of Innovative Technology Pathway; ITEM Coalition Letter to Office of Management and Budget regarding low vision device coverage; ITEM Coalition Position Statement on Low Vision Devices and Assistive Technologies: ITEM Coalition Letter to CMS and OMB; ITEM Coalition Comment on FY2022 DMEPOS proposed rule

Medicaid and the Children's Health **Insurance Program (CHIP)**

Medicaid and CHIP are a necessary access point for low-income adults and children to access essential vision and eye care. Eye health services such as vision screenings, eye examinations, eyeglasses, and medical or surgical procedures, are considered covered services under Medicaid and CHIP for children under the age of 21. Typically, states determine what kind of vision and eye health services for adults are offered under their own Medicaid programs.

As a result of increased enrollment due to the economic consequences of the pandemic, states may be facing challenges in maintaining enrollment and scope of services. Without policy interventions at the federal level (such as directing additional funding to states to ensure continuous coverage), states could cut services such as vision and eye care (which are typically considered optional services) or tighten eligibility restrictions. This would result in patients who may need coverage options to manage chronic conditions being dropped from their coverage in order for states to meet budget shortfalls. In addition, the Trump Administration has relied heavily on Section 1115 waivers through

introduction of its "Healthy Adult Opportunity" guidance, which sought to devolve federal management of Medicaid to states through broad waiver flexibility and has resulted in narrow program eligibility or reduced services, including vision and eye health.

Policy Outlook and Positioning:

Should the Supreme Court decide in the spring of 2021 to overturn the ACA, a number of Medicaid-related policies including state-based Medicaid expansions and Section 1115 waivers, will be impacted. Should the Court uphold the ACA, the Biden Administration can be expected to reverse a number of Trump-era policies; though the process for doing so will be lengthy and complex. The Biden Administration is likely to issue new guidance or use regulatory approaches (such as encouraging states to use waivers to expand their programs) to protect Medicaid expansion and accomplish broad objectives (such as health equity) and ensuring enrollees can remain covered through the duration of the pandemic. In addition, President Biden can be expected to eliminate the 5-year waiting period before lawfully-present immigrants are able to enroll in Medicaid or CHIP.

Because children and families and increasingly non-elderly adults with and without disabling conditions rely on Medicaid to access vision and eye care services, Prevent Blindness reinforces our support for policies that protect Medicaid expansion and sustain enrollment levels without eliminating vision and eye health care and services - including vision screenings, eye examinations, treatments, correction for refractive errors, and chronic disease management services. Children with untreated vision problems become adults with untreated vision problems who may experience higher risk of poor health outcomes, lower levels of education attainment, and fewer economic prospects without early and preventive care.

We encourage states to consider vision and eye health as a part of overall health, and to integrate vision into appropriate disease and behavioral (such as smoking cessation) interventions. Prevent Blindness will also continue our advocacy efforts alongside patient groups and health advocates in efforts to stabilize

The Affordable Care

Medicaid from some of the effects of the COVID-19 pandemic.

Prevent Blindness Advocacy:

Prevent Blindness Statement on "Healthy Adult Opportunity" Medicaid Guidance; Prevent Blindness Comment on SUNSET proposed rule; Prevent Blindness Comment on Medicaid Maintenance of Effort interim final rule; Families USA Letter to Congress requesting state and local relief for Medicaid; Georgetown University Center for Children and Families Letter re: Work Requirements in Medicaid

Affordable Care Act

The ACA requires insurers offering health plans through state-based exchanges to cover services related to 10 established categories of care, or "essential health benefits" (EHBs). EHBs include pediatric vision care services and chronic disease management for adults. Unfortunately, health reform efforts have targeted EHBs as a driver of high consumer out-of-pocket costs for obtaining health coverage, particularly by indicating not all EHBs (for example, maternity care) are suitable for all consumers, thus requiring them to pay for unnecessary coverage. This has led to the emergence of short-term, limited duration plans as a coverage option for healthier adults as these plans are not required to provide EHBs or minimum essential coverage.

According to the Centers for Medicare and Medicaid Services, short-term, limited duration health plans, which provide stopgap insurance coverage to individuals for up to 364 days and no more than 36 months, are exempt from the ACA's definition of individual health insurance coverage that requires a minimum of essential health coverage; thus, allowing for premiums to be lowered enough for patients to meet coverage requirements without facing high costs for premiums and deductibles. Short-term plans, which are typically only suitable as a stopgap option for consumers who may be in between coverage enrollment periods, may be attractive to healthier patients (whose utilization may be minimal), but they do not offer protections

against denial for preexisting conditions, EHBs, and may impose limits on care provided. Thus, consumers may be left on the hook for costs associated with uncovered care.

Policy Outlook and **Positioning:**

As part of policy efforts to address high premium costs and out-of-pocket deductibles for coverage options

Act includes 10 categories of essential benefits and services, called "essential health benefits." **Pediatric vision care** and chronic disease management are essential health **benefits** required to be covered under ACAmarketplace plans.

under the ACA marketplace and prior to the repeal of the ACA's individual mandate, the Trump Administration sought to bifurcate short-term limited duration and association health plans from the regulations that govern traditional health plans so that consumers would be considered covered under the individual mandate and not be subject to high premium costs for ACA plans. Prevent Blindness has worked with stakeholders, coalitions (such as I Am Essential, which seeks to protect EHBs), and like-minded organizations to safeguard EHBs as a base level of coverage offered on all marketplace insurance plans, and to find cost-saving solutions for consumers that encourage and promote enrollment through state exchanges.

A ruling on California v. Texas by the Supreme Court on whether the ACA in its entirety (including EHBs) should be invalidated is expected in the spring of 2021, which will determine the Biden Administration's course of action on the ACA. Immediately, the Biden Administration may act to reopen HealthCare.gov enrollment as a means of ensuring continuity of coverage during the pandemic, bring regulatory efforts such as waivers that weaken the ACA's patient protections to a halt, and implement changes that nullify short-term, non-ACA plans. In addition, Administrative action may work to increase premium subsidies under the ACA,

capping premiums for all enrollees at 8.5% of income, and restore funding for outreach efforts that encourage enrollment.

Prevent Blindness Advocacy:

I Am Essential Coalition Comments on Notice of Benefit and Payment Parameters for 2020; I Am Essential Coalition comments on Section 1557 regulations; I Am Essential Coalition comments on Notice of Benefit and Payment Parameters for 2021

Private Insurance

Vision insurance policies, which are often separate policies from health insurance plans, typically (but not always) cover the cost of eye examinations as well as eyeglasses or contact lenses to correct refractive errors, though usually up to a certain point. Vision insurance can facilitate referral and follow-up to specialty care if symptoms of serious eye diseases are noticed during an eye exam. However, not every working adult has access to employee-sponsored vision insurance or has the option or financial capability to obtain a stand-alone plan or cover out-of-pocket expenses, including copays and premiums. Patients who cannot afford outof-pocket costs associated with vision insurance plans may be likely to forgo eye care altogether; particularly if the costs compound for covered family members or children. Additionally, patient uncertainty about the scope of benefits included in their coverage policies may deter them from getting specialty eye care or preventive screenings for conditions such as diabetes that may help prevent eye diseases from developing or progressing.

Policy Outlook and Positioning:

As payers undergo periodic reviews of coverage policies and benefit designs, integrating vision and eye health, including regular eye examinations and coverage of eyeglasses, into medical coverage can help achieve quality and outcomes benchmarks and reduce costs to the patient and the system by catching problems early. Patients seeking eye care would benefit from certainty in costs, benefits, and plan designs, which can help motivate and empower patients to obtain preventive eye care as well as adhere to prescribed eyewear and treatment plans.

Through our coalition partners and information channels, Prevent Blindness will continue to monitor developments in federal or state policy to ensure that changes affecting payers and plan design are balanced with the aggregate impact on patients and families. As well, engaging in these conversations will help break down siloes of care between health insurance and vision insurance and accomplish other Prevent Blindness goals of integrating vision and eye health into other appropriate clinical interventions on chronic disease, aging, and mental health and utilizing the primary care setting as a natural access point for disease prevention and health promotion.

Prevent Blindness Advocacy:

National Health Council Comment Letter: Notice of Benefit and Payment Parameters for plan year 2021 and 2020

Lack of insurance coverage delays early detection and treatment of progressive eye diseases such as glaucoma, which leads to permanent and irreversible blindness if not detected and treated early.

National Academies of Sciences, Engineering, and Medicine

CHILDREN'S VISION AND EYE HEALTH



Healthy vision in children contributes to improved school readiness, learning capability, improved motor and cognitive development, social and emotional well-being, and lifelong productivity. Vision disorders affect nearly 13.5 million children in the United States, and are the 4th most common disability in children in the U.S. Despite its importance to overall health and development, children often face a fractured system of care that leaves them vulnerable to conditions that could lead to permanent vision loss without appropriate interventions.

Prevent Blindness recommends a continuum of eye care for children that includes both vision screening and comprehensive eye examinations as a complementary approach to children's vision and eye

Children ages 3 to 5 years *had* not yet seen an eye care

63.5%

Vision Testing Among Children Aged 3-5 Years in the United States 2016 - 2017

provider.

health. In addition, we promote policies that seek to realize a systems-level approach to children's vision and eye health in areas of national surveillance, uniformity of screening best practices, reducing disparities in vision and eye care, and program accountability efforts. Each of these practices, when deployed together, will lead to a better use of limited resources and improve population health.

Early Detection and Intervention

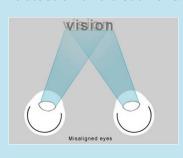
Unlike other senses, which are fully functioning at birth, a child's vision develops and changes throughout their early childhood years. Early intervention techniques like screening, detection, diagnosis, and treatment protocols are therefore necessary contributors to an effective public health approach to children's health while lessening health disparities and improving vision and eye health outcomes for children. A child's vision can change quickly as they age, requiring the need for consistent surveillance and screening protocols.

Despite the benefits of early detection and intervention in preventing avoidable vision loss in children, significant access issues such as costs or inability to obtain coverage for vision and eye care, as well as the absence of a national surveillance mechanism to track screenings, follow-up exams, treatment, health outcomes, and population data continue to be a significant public health challenge in measuring progress and coordinating care across systems. Additionally, there is wide variability in state-level laws and approaches for children's vision screening in preschool and school-aged children. As such, wide disparities in eye health status persist for children entering preschool or school.

Policy Outlook and Positioning:

Early detection and intervention for vision disorders in children are part of national goals and health care standards, such as Healthy People 2030 and the U.S. Preventive Services Task Force's 2017 recommendation that children ages 3 to 5 years should receive a vision screening. Prevent Blindness has informed lawmakers about the gaps that exist in children's vision and

Untreated strabismus (crossed eye) and amblyopia (loss of or reduced vision in an eye) affects healthy development and will lead to permanent vision loss without early detection and treatment.



eye health at the national level with recommendations for how to integrate children's vision and eye health into existing programmatic interventions that prioritize early detection and intervention. Our advocacy focuses on areas within Title V (Maternal and Child Health) programs where it is most natural for national and state level reporting measures for children's vision and eye health to be

implemented or integrated in existing developmental programs and ensuring that federal appropriations are sufficient to meet program priorities.

In addition, Prevent Blindness, alongside other public health and issue-based stakeholders, has advocated through the federal appropriations process for agency-level increases to the Health Resources and Services Administration and its Maternal and Child Health Bureau and the Centers for Disease Control and Prevention and its Vision Health Initiative. With adequate funding levels, states and communities can integrate evidence-based children's vision health efforts into public health interventions and ensure a multilevel

response to preventing vision loss promoting eye health as a natural element of children's overall health and wellbeing.

In his campaign for presidency, President Biden signaled an intent to employ early childhood development experts in community health centers and in pediatrician offices with a high percentage of Medicaid and Children's Health Insurance Program patients to help foster a primary care team to ensure children are reaching development milestones, and that care and services are being coordinated for families as needed. Prevent Blindness will monitor these policy developments to ensure that children's vision and eye health professionals, employing best practices, are included.

Prevent Blindness Advocacy:

Prevent Blindness Position Statement: Children's Vision and Eye Health; Developing a Consensus on a Systems-Based Approach to Children's Vision and Eye Health; Prevent Blindness Position Statement: Children's Sports Eye Safety; Prevent Blindness Vision Screening Requirements by State; Children's Budget Coalition COVID-19 relief letter; Friends of HRSA FY21 request and FY20 request; Friends of Title V FY21 request and FY20 request

School-Based Health Care

School-based care ensures that children have direct access to essential health services regardless of race, ethnicity, family status, means of accessing care. A



26 states

require vision screening for preschool-age children (ages 3-5). 41 states

(including Washington, DC) require vision screening for school-age children (ages 6-17).

Prevent Blindness, National Center for Children's Vision Eye Health recent study from the Children's Health Fund identifies vision as a health-related barrier to learning. Eliminating barriers to care, such as income, transportation or parental time away from work, promotes early intervention in the setting where children are learning and developing and at age-appropriate intervals. School nurses, community health workers, and other trained professionals are an indispensable piece of the schoolbased health care model.

Vision screening in school-aged children (ages 6 years to 17 years) differ from protocols for children aged below 5 years. Vision screenings for young children in a school-based setting—using recommended tools, protocols, and procedures—is a cost-effective method to identify children in need of evaluation and treatment by an optometrist or ophthalmologist. Early diagnosis and treatment of vision disorders will allow for more normal visual development; prevent further loss of vision; and may decrease the impact of learning problems, poor school performance, developmental delays, and behavior concerns. At the preschool level, children are required to have a vision screening completed upon entry into Head Start and Early Head Start programs while vision screening requirements and capacities for elementary, middle, and high school students vary across states and local school districts. Currently, 41 states require vision screening for school-age children and 26 states require vision screening for pre-school aged children. Additionally, intervals of vision screening between grades vary widely.

Policy Outlook and Positioning: Prevent

Blindness endorsed H.R. 2075, the School-Based Health Centers Reauthorization Act, which passed the House in September 2020. This legislation would reauthorize the long-lapsed School-Based Health Centers program at the Health Resources and Services Administration. The end-of-year combined COVID-19 relief and FY21 omnibus legislation, which passed the House and Senate in December 2020, reauthorized this program for four years starting in 2022. In addition, Prevent Blindness joined with the National Head Start Association to advocate for additional funding to Head Start and Early Head Start programs as part of COVID-19 response effort. Congress directed nearly \$1 billion over several supplemental appropriations bills to these essential programs.

The COVID-19 pandemic, which has decimated schools' capability to provide essential services, has only heightened the need to invest in school-based health services as this is often the only entry point to receiving eye care that children encounter. Without these services, families may be forgoing or unable to access essential services that can help detect and treat vision conditions before they progress. As school systems implement approaches for safely returning to in-person learning, children's vision and eye health may face competing demands for school-based health services including personnel to conduct vision screenings and coordinate care, safe administration protocols, and protective equipment. This reinforces the need to work with likeminded organizations to achieve shared goals around adequate investments in school-based and community health capacities to meet all needs.

Prevent Blindness will also continue to identify new partners at agencies such as the Healthy Schools program at the Centers for Disease Control and Prevention or the Federal Partners in School Health Interagency Workgroup to provide guidance from our National Center for Children's Vision and Eye Health to state and local education agencies.

Prevent Blindness Advocacy:

Children's Vision Screening Considerations During the COVID-19 Pandemic; Prevent Blindness Position Statement on School-Aged Vision Screening and Eye Health Programs; National Head Start Association letter requesting Head Start funding in COVID-19 relief; School-Based Health Alliance Letter endorsing reauthorization of the School-Based Health Centers Reauthorization Act

Maternal and Child Health

Maternal health, particularly prenatal care, the health of the mother at the time of pregnancy and through duration, the mother's socioeconomic circumstances, and her child's health outcomes-including vision and eye health-are interconnected. Increased attention to the maternal mortality crisis has led to a broader

Because policy efforts to improve maternal health have downstream benefits for children's health and development, including vision and eye health, **Prevent Blindness** has increasingly lent support to the efforts of organizations whose core missions are improving maternal health.

discussion of the importance of ensuring pregnant women have access to the care vital to her health and her child's health throughout pregnancy. Policy efforts to ensure first that the mother is healthy during and after her pregnancy can lead to a secondary policy outcome of safeguarding the child's health through gestation and after birth. Women can also experience changes in vision throughout the span of her own lifetime, including through pregnancy; thus, underscoring the role that her own health

plays in support of the health of her child.

Policy Outlook and Positioning:

Policy efforts to improve maternal health have included expanding the length of postpartum coverage under Medicaid, increasing access in rural areas, implementing evidence-based quality improvement efforts in perinatal care, and addressing systemic disparities across racial and ethnic populations in health care delivery. These approaches all have downstream benefits for children's health and development, including vision and eye health. Prevent Blindness has therefore increasingly lent support to organizations whose core missions are improving maternal health; specifically, by endorsing H.R. 4995, the Maternal Health Quality Improvement Act and H.R. 4996, Helping MOMS Act, which would, respectively, improve rural health maternal access and extend postpartum coverage through Medicaid. In addition, Prevent Blindness endorsed H.R. 2507, the Newborn Screening Saves Lives Act, which passed the House in July 2019, to extend federal newborn screening programs at the CDC, the National Institutes of Health, and the Health Resources and Services Administration

and makes improvements in surveillance of newborn conditions. The 116th Congress failed to enact these bills; however, the 117th Congress will likely introduce and reconsider them.

More work is necessary to understand and address children's visual development within the 0-3year age range, particularly as deficits to visual health and neurodevelopment are a consequence of premature birth, low birth weight, maternal smoking, opioid, and other substance use during pregnancy, contraction of the Zika virus and, possibly, the 2019 coronavirus. To that end, Prevent Blindness continues to support annual and emergency appropriations to the Emerging Threats to Mothers and Babies Surveillance program at the CDC's National Center for Birth Defects and

Developmental Disabilities, and identify new opportunities that address neonatal abstinence syndrome.

Prevent Blindness Advocacy:

Prevent Blindness Seeing the Way to Better Health: Women's Health and Vision Health: Prevent Blindness Fact Sheet: Pregnancy and Your Vision; Prevent Blindness Fact Sheet: Zika Virus and Your Eyes; Newborn Screening Saves Lives Reauthorization Act sign-on letter; Surveillance for Emerging Threats to Mothers and Babies FY20 funding support letter and COVID-19 supplemental appropriation support letter

A 2010 report from the Office of the Inspector General at the Department of Health and Human Services determined that

76% of children did not receive all required **EPSDT** screenings, including vision screenings.



Early Periodic Screening, Diagnosis, and Treatment (EPSDT)

Medicaid and CHIP are required to provide eligible child enrollees with an Early and Periodic Screening Diagnosis and Treatment (EPSDT) benefit, which is designed to screen, diagnose, and treat children at early and appropriate intervals of care. The EPSDT benefit includes medical, dental, hearing, and vision services and each state establishes its own periodicity schedule, typically by age, and based on Bright Futures guidance from the American Academy of Pediatrics and the Health Resources and Services Administration. Using state-reported information (states are not required to report vision or hearing screenings), the Office of the Inspector General (OIG) at the Department of Health and Human Services (HHS), in 2010, determined that 76% of children across 9 states did not receive all required EPSDT screenings with more than half not receiving any required vision or hearing screenings. In a follow-up report in 2014, the HHS OIG recommended that CMS require states to report vision and hearing screenings and increase collaboration with states to encourage both beneficiary and provider incentive to participate in and conduct EPSDT screenings.

Policy Outlook and Positioning:

In his campaign for presidency, Biden signaled that he will direct his Secretary of Health and Human Services to ensure that all eligible children receive EPSDT services. Prevent Blindness will work with HHS in 2021 - 2022 as part of our goal to increase the percentage of children in Medicaid and CHIP who receive a vision screening and any necessary follow-up eye care. As recent data from CMS indicates that child service utilization in Medicaid and CHIP, including screenings, dropped dramatically during the COVID-19 pandemic, Prevent Blindness will particularly advocate for policy changes such as provider reimbursement, accountability measures, and requiring that results of vision screening and completion of referral to eye care are reported, as recommended by the HHS OIG report. This will ensure that children do not suffer long-term consequences of delayed eye care and treatment. These policy efforts may require advocacy to Members of Congress who have oversight of Medicaid

and CHIP, either as part of ongoing pandemic relief legislation or as separate policy efforts.

Prevent Blindness Advocacy:

Public Policy and Your Sight: Your Child's Sight;

Prevent Blindness Fact Sheet: Children's Screen Time

Digital Device Use and Vision

Assistive devices and technologies can help children with visual impairments quickly adapt to learning alongside their peers, which can complement emotional development and social engagement. Assistive devices can range from optical devices such as magnifying devices to increase font to non-optical devices such as closed-circuit televisions. Accessing these devices, and receiving the proper training, are often challenging to students for a number of reasons, including affordability. Unfortunately, with many schools nationwide transitioning to virtual classroom experiences during the COVID-19 pandemic, students who rely on assistive devices and adaptive technology for learning may often face compounding difficulties with maintaining quality of education during virtual learning; thereby potentially falling behind their peers.

Policy Outlook and Positioning:

Many of the effects and consequences of the COVID-19 The federal Individuals with Disabilities Education Act (IDEA) is an important law that establishes equality and equity in learning and education as national policy. Visual impairment and blindness, under IDEA, must be included in any state's definition of a disability in terms of providing procedures and resources and may not be narrowed to bypass special education and related service provision; a point that was clarified in a 2017 memorandum to state directors of special education from the Office of Special Education at the U.S. Department of Education. The challenges of the COVID-19 pandemic have placed enormous burden on schools to provide the same quality of learning in online or virtual classrooms as offered in in-person learning settings; however, students who are blind or have visual impairment may struggle with new challenges

of accessing educational means to ensure a seamless transition to online education settings and stay on task with learning experiences.

As a leader in children's vision and eye health, Prevent Blindness fundamentally reinforces the role of vision and eye health as an indicator of childhood academic performance and successful learning. We believe that all children-regardless of their visual capabilitiesdeserve to learn and succeed in school and have access to the services and technologies necessary to realize his or her potential in the classroom. As the 117th Congress and the Biden Administration continue to explore the needs of students, teachers, and other professionals in educational settings during the COVID-19 pandemic, Prevent Blindness will seek opportunities to work with stakeholders to reinforce the message of equitable learning.

Prevent Blindness Advocacy:

Children's Vision Massachusetts Resources

Access to Assistive Devices and **Technologies for Learning**

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ADULT VISION AND EYE HEALTH

Early detection, treatment, and consistent follow-up care to the aging eye, which is particularly susceptible to disease and conditions that affect the refractive state of the eye or its function and structure, are important aspects of aging with healthy vision and avoiding preventable vision loss and blindness. More can be done, however, to improve policies that address the aging population's vision and eye health needs by mobilizing programmatic action right where seniors need it most: in their daily lives, communities, and homes. In the absence of optometrists and ophthalmologists, primary care physicians, nurse practitioners, physician assistants, and other primary care providers can provide vision screenings at community and rural health centers. More research is needed to better understand how to use the existing infrastructure of community health organizations and established relationships with underserved and low-income communities. In addition. the COVID-19 pandemic has ignited policy efforts around how to best protect vulnerable Americans-including elderly and aging adults- from the devastating impacts of the current and future public health emergencies. All of these policy considerations must be considered to improve access to vision and eye care services right where Americans live, work, and interact with each other.

Vision in Primary Care Settings

Primary care can often drive better health outcomes. lower costs, and higher quality of care by emphasizing prevention of serious, complex conditions before they progress, and behavioral and lifestyle changes that promote health and wellness. Primary care settings offer a front-line opportunity for providers to conduct screenings, ask questions, and integrate vision and eye health into a patient's overall care management plan. Oftentimes, primary care providers can do little more than refer patients to an eye care specialist. There is, however, an opportunity with respect to eye disease prevention, notably with the advent of important technological advances that can transmit key eye health data from primary care centers. Interventions in the

primary care space can result in referrals to specialty eye care and improved electronic health records, thus facilitating provider-to-provider consultation and breaking down siloes of care between vision and eye health and overall health. Additionally, primary care, which often includes initial screenings to detect eye diseases, is often the entry point for patients into the broader health care system and thus a natural setting for early detection and interventional care in its role as the patient-centered medical home.

Policy Outlook and Positioning:

Public policy efforts to secure and retain a well-trained primary care workforce and infrastructure complement Prevent Blindness's vision and eye health advocacy and policy goals, particularly as several trends straining the primary care profession-including population growth, population aging, demographic changes, and access issues—are in lockstep with trends fueling our national vision and eye burden. As primary care professional organizations and thought leaders advocate for policy change that also benefit vision in primary care settings (such as reimbursement for screenings and models of care delivery that promote care coordination and health information technology), Prevent Blindness will evaluate

these efforts to ensure they will improve patient access to vision and eye health.

Prevent Blindness Advocacy:

Building Public Health Capacity to Enhance Vision and Eye Health: A Toolkit for Public Health Agencies and **Their Partners**

Healthy aging is a process, not an outcome. Unfortunately, attitudes about aging and accepting poor health outcomes as inevitable with getting older often preclude early detection and treatment efforts that are critical for healthy aging.

Aging with Healthy Vision:

While the aging eye is susceptible to a myriad of diseases that can affect sight and, while the mature eye undergoes many changes that can affect its function and one's ability to see clearly, loss of sight does not have to be accepted as inevitable with advancing age. Vision and eye health problems have a strong correlation to many other costly chronic health conditions - particularly many that increase in prevalence with age. Coordinating studies from the National Academies of Sciences, Engineering, and Medicine and others that older adults with untreated poor vision are more likely to suffer from Alzheimer's disease, cognitive decline, mental health issues, including depression and social isolation, and dementia. Healthy aging is a process, not an outcome. Unfortunately, attitudes about aging and accepting poor health outcomes as inevitable with getting older often preclude early detection and treatment efforts that are critical for healthy aging. The Centers for Disease Control and Prevention estimates that diagnosis and early treatment could prevent a majority of visual impairment and blindness in the U.S. Emphasizing preventive vision and eye care can help aging patients not only retain their sight and quality of life but avoid the serious health risks that come with diminished vision, including: injury or death from falls, costly chronic conditions, diminished mental and emotional health due to loss of independence or ability to engage in personal

Aging health policy must also ensure adults with age-related vision issues are connected to available necessary community services and assistance programs that can help them adapt to their changing vision and age healthfully.

hobbies or exercise, and social isolation and loneliness.

Policy Outlook and Positioning:

In March 2020, Congress passed legislation reauthorizing the Older Americans Act (OAA), through Fiscal Year 2024. The OAA includes disease prevention and health promotion services such as routine screening for glaucoma, vision, diabetes, and other conditions that are co-morbid with vision impairment and eye

disease. Prevent Blindness recommended to the House Education and Labor Committee that the bill should strengthen the role of vision and eye health services, including low vision and assistive technologies for people who live with low vision, under the OAA. Prevent Blindness also worked with stakeholder groups in the aging health and services community to advocate specific enhancements to the bill language, including healthy aging, falls prevention, chronic disease selfmanagement, and social isolation-recommendations that were ultimately adopted in the final bill.

In May 2020, in response to emerging impacts of the COVID-19 pandemic on elderly populations, Prevent Blindness endorsed H.R. 6935, the Protecting the Health of America's Older Adults During COVID-19 and Beyond Act, to create a "Healthy Aging" and COVID-19 Resource Center for Older Adults at the Centers for Disease Control and Prevention. While the House included \$10 million to fund this effort in its FY21 Labor-HHS-Education spending bill, it was not included in the final FY21 appropriations legislation. Should the 117th Congress reconsider these efforts, Prevent Blindness will assess our position in the context of how vision and eye health in aging populations can be improved.

Prevent Blindness Advocacy:

Prevent Blindness Letter to House Education and Labor Committee on OAA reauthorization; Prevent Blindness joins letter to Congress urging policies to protect older Americans during pandemic; Global Coalition on Aging Brief: A Life Course of Healthy Vision: A Critical Priority for the 21st Century; Prevent Blindness endorses legislation to create a "Healthy Aging" and COVID-19 Resource Center for Older Adults

Falls Prevention and Risk Assessment:

Elderly falls can set off a cascade of deteriorating health impacts and significant cost, making their prevention an essential aspect of aging health. While elderly falls can also occur due to a number of reasons unrelated to vision, several well-characterized visual functions,

46.7% of

adults aged 65 and older with severe vision impairment or blindness have also experienced a fall.

27.7% of

adults over age 65 without severe vision impairment or blindness have experienced a fall.

https://www.cdc.gov/mmwr/volumes/65/wr/mm6517a2.htm

including uncorrected or poorly corrected visual acuity, lack of contrast sensitivity, and decreased visual field loss, are all strongly associated with fall risk. Interventions that do not assess a patient's visual function and risk of blinding eye disease and connect patients to needed eye care represent a missed opportunity to prevent falls before they occur. In addition, home modification interventions that do not assess hazards such as poor lighting perpetuate an unnecessary risk environment for preventable falls.

Policy Outlook and Positioning:

In 2019. Prevent Blindness issued recommendations to the Senate Aging Committee's request for stakeholder input on falls prevention. Prevent Blindness recommended policies that enable stronger visionspecific interventions (such as home modification and environmental risks) by vision rehabilitation professionals, preventive vision assessments as part of a multi-component falls reduction strategy, vision and eye health services in the Medicare program (including those offered in the annual "Welcome to Medicare" exam), and including vision as part of transitions of care in home care populations.

The Senate Aging Committee's follow-up report on falls prevention acknowledged the role that vision and eye health plays in falls prevention, and recommended home care provider education and stronger data collection on falls. However, the Committee report did not include recommendations on improving existing interventions to integrate vision and eye health as a preventive measure. Additional advocacy is needed to direct federal resources to programs such as the Vision Health Initiative at the Centers for Disease Control

and Prevention (CDC), which will be used to update surveillance data on vision and eye health, strengthen consistency in vision assessment practices, and develop evidence-based guidelines across programs such as Stopping Elderly Accidents, Deaths, and Injuries (STEADI) and others.

The Senate Aging Committee's report recommended "continued investment in the development of and expanded access to evidence-based falls prevention programs to ensure greater awareness of the risk of falls among older adults and promote preventive steps that can be taken to avoid a fall." In follow-up to this recommendation, the National Council on Aging sent a letter, which included Prevent Blindness as a signee, to House and Senate appropriators requesting \$10 million for falls prevention programs at the Administration for Community Living and \$4 million to the CDC's National Center for Injury Prevention and Control in Fiscal Year 2021. While Congress did not allocate this requested funding in the final FY2021 appropriations legislation, Prevent Blindness will continue to join efforts to advocate for this essential funding as part of a falls prevention advocacy strategy.

Prevent Blindness Advocacy:

Prevent Blindness joins National Council on Aging effort to secure falls prevention funding; Prevent Blindness letter to Senate Aging Committee on falls prevention

Cognitive Decline:

Vision is one of the sensory enablers of interpersonal connection, information processing, decision-making, and independence; therefore, researchers are increasingly looking to vision loss as a potential risk factor for cognitive decline in elderly adults. A 2019 Morbidity and Mortality Weekly Report (MMWR) from the Centers for Disease Control and Prevention found that subjective cognitive decline, including frequent or worsening confusion or memory loss, affected over 11% of adults aged 45 years and up with 18% of adults having a vision impairment.

Maintaining healthy vision in the aging process can play a role in protecting cognition and avoiding the associated consequences of decreased quality of life, disability, social isolation, depression, loss of memory, and declining health status. As

age, staying ahead of 18% of adults

over age 45 years reported having both a visual impairment and subjectivecognitive decline related functional limitations, compared to only

4% of adults who

reported not also having a visual impairment.

Vision Impairment and Subjective Cognitive Decline-Related Functional Limitations, 2015 - 2017

cognitive decline has become part of research efforts to determine whether early response to cognitive decline can be achieved through vision and eye health prevention, health promotion through public education and awareness of risk factors, and treatment.

our population continues to

Policy Outlook and Positioning:

Emerging initial evidence of the link between vision impairment and cognitive decline underscores the need for continued federal investments in research at the National Eye Institute at the National Institutes of Health to verify the link between cognitive decline and vision health and determine its causes. Prevent Blindness will continue to support these investments as part of a broad strategy that emphasizes early detection, intervention, and treatment of vision problems in both non-elderly and elderly populations.

Prevent Blindness Advocacy:

Prevent Blindness Fact Sheet Seeing the Way to Better Health: Brain Health and Vision Health

Vision and Eye Health Safety:

Vision is essential to one's ability to work and engage with the world around them, but it is often an afterthought in work, home, or recreational settings. Even minor injuries, such as a foreign object in the eye or dry eye resulting from prolonged computer screen use, can inhibit a person's productivity and lead to impaired sight, increased costs, and diminished quality of life.

Vision and eye health safety messaging into public education and policy efforts, such as those at the state level that govern the use of fireworks, can help people understand risks and avoid injuries that could damage the eye structure and potentially contribute to vision impairment. Similarly, as contact lenses are classified as a medical device through the U.S. Food and Drug Administration (FDA) and through public health guidance from the Centers for Disease Control and Prevention (CDC) on contact lens use (particularly as the COVID-19 pandemic places contact lens wearers at increased risk of infection), ongoing patient education and awareness of risk to vision and eye health in personal care settings is necessary for prevention efforts. Likewise, regulations to safeguard the workplace must prioritize eye safety in occupational settings,

including protective eyewear for responders on the front lines of the COVID-19 pandemic.

Policy Outlook and Positioning:

Recent policy efforts to consolidate the National Institute of Occupational Safety and Health (NIOSH) at the CDC into the National Institutes of Health would remove occupational vision and eye safety research and promotion out of the public health space. Federal appropriation levels to the



The annual cost of workplace eye injuries due to lost productivity, medical treatment, and worker compensation.

Occupational Safety and Health Administration, U.S. Department of Labor

Department of Labor's Occupational Safety and Health Administration (OSHA) will need to be monitored to ensure continuity of enforcement and ultimately the protection of those who face potential occupational hazards that pose dangers to their vision and eye health. On the state level, many of Prevent Blindness's statebased affiliate chapters are actively engaged in fireworks safety advocacy and public education measures to help the public avoid the risks of avoidable injury and vision loss due to fireworks use and misuse.

Prevent Blindness Advocacy:

Prevent Blindness Fireworks Position Statement; Prevent Blindness Cosmetic and Decorative Contact Lens Position Statement; Stakeholder letter requesting PPE, including eyewear, to COVID-19 front line responders

Living with Low Vision:

The National Eye Institute defines low vision as a degree of visual loss or impairment that cannot be corrected with typical eyeglasses, contact lenses, or with various surgical procedures. Low vision does not refer to a total state of blindness as some vision remains, but vision challenges may affect one's central vision, peripheral vision, or ability to see in low light conditions. Low vision can be caused by eye diseases, genetic disorders, or trauma to the eye or brain as with an injury. In most cases, assistive technology can aid a person to experience a greater and fuller quality of life.

For people who have low vision, particularly those who are visually impaired or blind, policies must align to ensure that they can live safely, fully, and independently. People with low vision experience a range of greater needs than individuals with healthy vision and must therefore have access to the tools and services they require to meet their unique needs. Adapting to a life with low vision oftentimes requires rehabilitative services with professionals who specialize in low vision and visual rehabilitation who can care for the low vision patient's condition and help improve the system of

care for patients to achieve overall quality of life and life satisfaction. Communities can be equipped to connect with patients who live with low vision by partnering with professional groups, providers, and public groups to ensure those in their community who live with low vision have access to treatment, rehabilitation services, and support networks.

Policy Outlook and Positioning:

Addressing low vision in public policy first requires significant education to lawmakers and policy professionals about what constitutes low vision, what an individual living with low vision needs to maintain wellbeing, and identifying what mechanisms enable professionals who are best credentialed in low vision and vision rehabilitation to specifically treat low vision patients. As part of these efforts, Prevent Blindness is a member of Vision Serve Alliance to identify policy levers that will bring the needs of the low vision community to the forefront of conversations around disease prevention, aging health, disability advocacy, and provider capacity.

Prevent Blindness Advocacy:

Living Well with Low Vision



CHRONIC DISEASE PREVENTION AND HEALTH PROMOTION

A Robert Woods Johnson analysis ranks eye disorders as the seventh leading chronic condition-requiring ongoing treatment and management for the duration of one's life— across all age groups. Chronic health conditions can lead or contribute to vision problems and poor eye health or exist as a comorbid condition with vision problems. As learned during the pandemic, several conditions associated with the most serious complications of COVID-19 are analogous to vision and eye health, including diabetes, heart problems, depression and social isolation, longer hospitalization and readmission, and need for long-term care.

Disease prevention and health promotion are two strategies that, when deployed together, can foster



A report from the NASEM recommends that the Secretary of the U.S. **Department of Health** and Human Services should issue a call to action to motivate nationwide action toward achieving a reduction in the burden of vision impairment across the lifespan of people in the

National Academies of Sciences, Engineering, and Medicine 2016

United States.

greater individual and public awareness of the link between vision loss and eye disease and both modifiable and unmodifiable risk factors. as well as how patients can prioritize and access vision and eye care. Additionally, maintaining good vision and adhering to recommended vision treatments can have a beneficial effect on chronic disease management. By aligning with broad chronic disease prevention efforts and promoting overall health and wellness. Prevent Blindness can contribute to a reduction in the national prevalence of vision problems and eve disease.

Integrating Vision and Eye Health:

Like numerous chronic conditions, vision problems and eye disease—whether singularly or compounded with other costly conditions—are a significant driver of health care costs, diminished quality of life, and reduced economic productivity. Broad efforts to improve community access, address chronic disease, enhance connectivity to support services, and promote independence, economic well-being, and enhance quality of life across the age spectrum too often exclude vision and eye health. Without integrating vision care with other aspects of the health care system, patients with visual impairments will remain disadvantaged in these settings and health disparities will remain. Integrating evidence-based vision health efforts into public health interventions ensures a multilevel response to preventing vision loss and promoting overall eye health without drawing critical resources away from equally important public health efforts.

Policy Outlook and Positioning:

Addressing these substantial costs and improving health care quality, coordination, and outcomes will remain a major thesis of national health policy. The alignment of vision problems with these cost drivers creates a natural space for vision and eye health to be included as part of the solution.

By partnering with numerous coalitions and interest groups on opportunities to endorse legislation, sign on to regulatory and Congressional sign-on letters, gathering information through attendance at issue forums, and developing ongoing relationships with diverse interest groups in health policy, Prevent Blindness has raised the profile of preventable vision loss and eye disease as a national endemic with profound impacts across all age groups. As part of this messaging strategy, in June 2019, Prevent Blindness joined with other partners to meet with U.S. Surgeon General Jerome Adams to request, per the recommendations of the 2016 National Academies of

Sciences, Engineering, and Medicine report, a "Call to Action" on vision and eye health.

Prevent Blindness Advocacy: Prevent

Blindness Resource: Integrating Vision Programs; Prevent Blindness response to HHS Prevention X Initiative; Prevent Blindness response to CDC's Community Preventive Services Task Force; Vision 2020 USA Letter to Surgeon General Jerome Adams; National Academies of Sciences Engineering and Medicine: Making Vision Health a Population Imperative: Vision

COVID-19 and Vision Health:

The coronavirus pandemic has revealed where significant disparities in health equity and access exist, particularly for vulnerable communities such as the elderly, racial and ethnic populations, low income communities, and those who live with chronic diseasesincluding vision loss and eye diseases. The results of the Flatten Inaccessibility survey, which was co-managed by fifteen organizations (including Prevent Blindness) that were interested in gauging the effects of COVID-19 on adults with visual impairment, indicates that our nation has failed to address the needs of those who live with visual impairment and eye disease and anticipate their needs ahead of this public health emergency. Additionally, the pandemic has shed a new light on many policies, such as telehealth, that existed prior to the pandemic but require new considerations as policymakers look to make permanent policy changes.

Federal Outlook and Advocacy:

Addressing the COVID-19 pandemic has continued to rely on emerging and changing science and public health practices in addition to shifting leadership in the White House and in Congress. Navigating these changes in the present will require reflecting on lessons learned in the past in an effort to apply them in future pandemic responses or even natural disaster responses that may present patients with disruption in vision and eye care treatment. As such, advocacy efforts must reflect shortterm public health and response goals that may change

The <u>Flatten Inaccessibility</u> survey determined that:



68% of participants feared they would not be able to get themselves or loved ones to COVID-19 test sites or their healthcare providers if they got sick.





59% of participants felt their underlying health conditions made them particularly vulnerable to COVID-19.



56% of participants feared their ability to social distance and ask for help, physical assistance, or using touch.



60% reported the technology needed for work and school was not accessible.



90% reported receiving no training in the new technology.

frequently. Long-term outcomes on vision and eye health will depend on the effectiveness of to-be-seen efforts in vaccine distribution, mitigating community spread, economic recovery efforts, and transitioning back to "normal" ways of life, school, and work.

Since the start of the pandemic in late February 2020, Prevent Blindness has used the opportunities presented in pandemic response efforts in Congress and the Administration and on the ground in states and communities to ensure vision and eye health is not absent from response and recovery efforts. Our advocacy has focused on short-term policy goals related to emergency response, mid-term policies related to ongoing disease management and adaption to a "new normal," and anticipating policies on long-term recovery that may cause societal disruption or impede access to care.

In response to the pandemic, Prevent Blindness aligned with our coalition partners and joined ad hoc advocacy efforts across organizations to: protect those who lost access to health care through employerbased insurance plans; ensure Medicaid solvency as states experienced enrollment surges; protect patient access to prescription drugs and medical supplies by advocating for relaxed policies that placed limitations on refills and personal emergency stockpiling; ensure that personal protective equipment (PPE)—including protective eyewear-was made available to front-line responders; and protect older Americans who are at greatest risk during the pandemic. Many of these efforts were successful through regulatory channels as well as legislative relief efforts during the spring.

With respect to vision and eye health, Prevent Blindness advocated to the Centers for Medicare and Medicaid Services (CMS) to ensure patients who rely on sight-saving treatments and therapies under Part B can, if needed, receive care in their home or personal care settings while adhering to social distancing and risk management protocols. In response, CMS issued guidance to providers allowing for home administration of Part B drugs. Prevent Blindness worked through the Coalition for Health Funding to encourage Congressional leaders to, in future COVID-19 relief legislation, prioritize vision and eye health research on the impact of

increased and prolonged device use for children and adults whose school and work settings transitioned to long-term virtual environments. In addition, as the Flatten Inaccessibility survey indicated the unique challenges that people living with low vision, severe visual impairment, or blindness face during the pandemic, Prevent Blindness has also increasingly aligned with organizations such as the American Council of the Blind on access issues, such as accessible voting during the 2020 primaries and general election. These efforts may continue at the state level into the 2022 midterm elections. Voting accessibility was also a main feature of 2020's World Sight Day.

Prevent Blindness also issued recommendations to a June 2020 Senate Health, Education, Labor, and Pensions (HELP) Committee inquiry on pandemic response, encouraging broader data collection on demographic, social determinants of health, and population health criteria to ensure future pandemic responses do not exclude people with unique vision needs, advocating for vision and eye health surveillance through the Vision Health Initiative at the Centers for Disease Control and Prevention and for a national children's vision and eye health surveillance program, ensuring continuity of care for people facing a sudden loss of health coverage, and making permanent the most beneficial telehealth flexibilities employed during the pandemic. Finally, Prevent Blindness elevated concerns to Congressional leadership that the recent drop in child health utilization services in Medicaid and CHIP—including early detection and screening for vision health services—could compound or exacerbate already existing access issues for children who need vision and eye care treatment.

Moving forward, the COVID-19 pandemic will continue to be the main health policy issue facing the Biden Administration and the 117th Congress; thus, requiring Prevent Blindness advocacy to determine how vision and eye health will be impacted by new policies and to shift focus toward ongoing response and management efforts, including ensuring that increased vaccine production does not create drug shortages for sight-saving treatments in thyroid eye disease and others.

Prevent Blindness Advocacy:

Prevent Blindness response to Senate HELP Committee inquiry on pandemic response; Stakeholder letter requesting PPE, including eyewear, to COVID-19 front line responders; Families USA letter urging Congress to secure healthcare access and coverage for families and children during COVID-19 crisis; Prevent Blindness joins American Council of the Blind coalition letter to urge Congress to protect voting rights for Americans with disabilities; Coalition for Health Funding letter to Congress outlining priorities for COVID-19 relief legislation; Prevent Blindness joins call to Congress to safeguard patient access to medication during COVID-19 pandemic; Families USA letter requesting state and local relief to safeguard Medicaid programs

monitoring, and treatment of diabetes-related eye disease a significant public health priority as early detection and treatment can help lower the risk of blindness by 90%. The National Eye Institute estimates that more than 2 in 5 Americans with diabetes are at some stage of diabetes-related retinopathy. Other blinding eye diseases such as cataract, glaucoma, and retinal detachment are also prominent in patients

with diabetes.

89%

of the U.S. population is not aware that eve complications caused by diabetes have no warning symptoms.

CDC Vision Health Initiative

Diabetes-Related Eye Disease:



Early detection and treatment of diabetic retinopathy can reduce the risk of blindness by

95 percent.

National Institute of Diabetes and Digestive and Kidney Disease

Diabetes is a significant costdriver in our national health care system, and is incredibly consequential on personal finances, quality of life, and productivity for patients who live with the disease. The Centers for Disease Control and Prevention's National Diabetes Statistics Report for 2020 indicates that 34.2 million Americans have diabetes and 88 million adults have prediabetes. Diabetes is the leading cause of blindness in adults with significant disparities in prevalence of Type 2 diabetes across racial and ethnic minorities. Patients who have diabetes may often be unaware of the damage occurring to their eyes, specifically in the early stages, which makes early detection, disease

Policy Outlook and Positioning:

Public policy efforts around diabetes typically centers upon whole-disease strategies such as ensuring patients can access affordable health care through public or private coverage options, lowering costs of insulin and prescription drugs, increasing funding for diabetes research at the National Institute of Diabetes and Digestive and Kidney Diseases at the National Institutes of Health as well as public health programs at the Division of Diabetes Translation (DDT) at the Centers for Disease Control and Prevention, and promoting prevention through public education and community-based health care strategies. These efforts align with Prevent Blindness's advocacy priorities of ensuring the Vision Health Initiative, which is housed within the DDT, secures the resources necessary to determine prevalence estimates on diabetes-related eye disease and develop evidence-based guidelines around early detection, disease monitoring, and treatment. Increasingly, social determinants of health and health equity as related to diabetes are gaining increased attention in health policy, which are also priorities for Prevent Blindness advocacy with respect to vision and eye health.

Looking ahead, the Biden Administration will likely review waivers to public coverage options such as Medicaid to ensure that patient protections against discriminatory practices, such as pre-existing conditions like diabetes, remain a fixture in health care coverage policies. Prevent Blindness will continue to encourage investments to federal vision and eye health programs that touch on diabetes through the federal appropriations process, and identify opportunities with diabetes-focused organizations to support diabetes programs and encourage vision and eye health integration.

Prevent Blindness Advocacy:

Loss of vision suddenly or over major impact on one's mental and emotional health



connection, engaging managing one's daily

Prevent Blindness Resource: Seeing the Way to Better Health: Diabetes and Vision Health: Prevent Blindness Toolkit: Diabetes and the Eyes

Vision and Mental Health:

Loss of vision—whether it happens suddenly or over time—can have a major impact on one's mental and emotional health given its significant role in interpersonal connection, engaging in hobbies or interests, independently managing one's daily activities, maintaining independence, and remaining physically active. Children and adolescents may struggle with social connection and academic or athletic performance as a result of vision impairment. In addition, lack of social acceptance from using visual assistive

devices (including eyeglasses) may deter children from adhering to eye care treatment. Older adults may face a compounding risk in health status stemming from inability to adapt mentally and emotionally to changes in vision, leading to distress, anxiety, or depression that may cause them to disengage from physical activity (which could lead to chronic illness) and social connection.

All Americans—no matter their age, health status, socioeconomic circumstances, or racial and ethnic background—deserve to live life with clear, healthy eyesight. As the research that establishes the strength of association between vision and mental health continues to emerge, changes in visual status and function due to the impacts to one's quality of life and life satisfaction have cost implications that policymakers should consider to decrease the overall burden of mental health.

Policy Outlook and Positioning:

Improving our nation's mental and behavioral health has received bipartisan support, and the Biden Administration can be expected to seek policies that improve mental and behavioral health access. As with other chronic or sight-threatening conditions and illnesses, advocating for policies and programmatic approaches that integrate vision and eye health into existing mental and behavioral health interventions will be essential to any advocacy efforts linking mental health and vision.

Ensuring that Americans have access to care in other disease areas can help contribute to a reduction in negative health outcomes that exacerbate our national mental health crisis, and promoting a message that emphasizes early detection, treatment, disease monitoring, and prevention of blinding eye conditions can also reduce individual burden of disease, improve personal social and financial circumstances, and improve quality of life. In addition, through our Advocacy, Support, Perspective, Empowerment, Communication, and Training (ASPECT) patient engagement program, Prevent Blindness will train patient and caregivers in advocacy best practices, building the necessary skills and knowledge to address the intersectionality of their mental health and vision impairment, and fostering avenues for peer-to-peer support in the process.

Social Isolation and Loneliness:

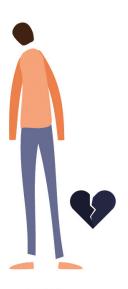
Americans of all ages and backgrounds are susceptible to the effects of social isolation and loneliness (particularly as social distancing has become necessary to mitigate community spread during the COVID-19 pandemic); however, older adults in particular are at increased risk of health consequences as a result of social isolation and loneliness. Older adults who lack strong community or social support networks may become increasingly lonely or socially isolated, which can have a bi-directional effect on health. According to the National Academies of Sciences, Engineering, and Medicine report Social Isolation and Loneliness in Older Adults: Opportunities for the Health Care System, diminishing sensory health, including vision, can cause or occur as a result of social isolation and loneliness which can in turn lead to increased risks for heart disease, stroke, cognitive impairment or decline, and mental health issues including depression and anxiety.

Policy Outlook and Positioning:

Public policy approaches to address social isolation and loneliness have placed an emphasis on building community-based services that promote social connection for older adults. One such piece of legislation, S. 2677, the Older Americans Social Isolation and Loneliness Prevent Act which supports screening for prevention of social isolation and loneliness and establishes processes to coordinate support services, was endorsed by Prevent Blindness and included in the 2020 reauthorization of the Older Americans Act.

The legislation also directs the Administration for Community Living to increase focus on social isolation and loneliness through the establishment of a federal interagency working group with aging network stakeholders. As these efforts evolve, Prevent Blindness will look for opportunities to engage with the workgroup to encourage vision and eye health as a natural aspect of social isolation and loneliness interventions and prevention.





Diminishing sensory health, including vision, can cause or occur as a result of social isolation and loneliness which can in turn lead to increased risks for heart disease, stroke, cognitive impairment or decline, and mental health issues including depression and anxiety.

National Academies of Sciences, Engineering, and Medicine 2020

POPULATION HEALTH



Since the 2016 release of the NASEM report outlining a national strategy on vision health, Prevent Blindness has convened expert advisors through **the** Center for Vision and Population Health to inform recommendations for policymakers to improve vision and eye health equity and access.

In 2016, the National Academies of Sciences, Medicine, and **Engineering** (NASEM) issued a report that defines vision and eye health as a population health concern due to the impact of vision problems on a large number of people, cost implications for individuals and systems, quality of life, and morbidity burdens; the increase in severity and prevalence, public perception as a threat to one's health, financial, social, and economic status; and can be addressed through community-level, public health interventions. Accordingly, the NASEM report included a number of recommendations that

made a direct call for federal government action around improving vision and eye health and equity in vision and eye health.

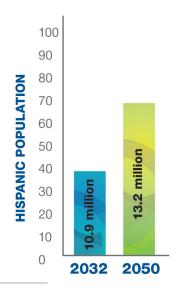
Objectives to improve vision and eye health must also factor in goals to improve health equity. Strategies to improve vision and eye health equity must include public awareness, a strong base of evidence, expanded access to clinical care, enhanced public health capacity, and community actions. Each of these actions must also be community-tailored, integrated, adequately resourced, collaborative, and culturally relevant. Since the report's release in 2016, these recommendations have formed the basis of Prevent Blindness policy and advocacy as we convene expert advisors through the Center for Vision and Population Health and inform recommendations to policymakers on improving vision and eye health on a population level and work towards

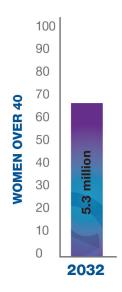
vision and eye health equity through the channels of public policy.

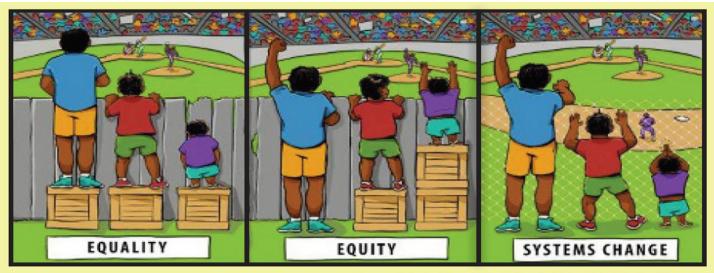
Equity in Vision and Eye Health:

Achieving health equity requires understanding the circumstances that lead to poor health outcomes in certain populations and tailoring responses that are appropriate to each affected population. Numerous studies and measures indicate where disparities in access to care exist along racial, ethnic, and socioeconomic lines, underscoring the need for policy to address gaps in vision and eye health across populations and to apply appropriate solutions per the NASEM recommendations.

Disparities in access to vision and eye health run across communities of color with increasing challenges likely to arise from anticipated demographic shifts to the population makeup of the United States. Based on forecasting trends from the NORC at the University of Chicago, prevalence of diabetes-related retinopathy in the Hispanic population is expected to increase by 35% (10.9 million) by 2032 and 63% (13.2 million) by 2050. This same report finds significant increase in vision problems among women (who have been determined as facing higher rates of eye disease, vision impairment,







Source: Adapted from Duke University Talent Identification Program

and blindness than men) with a projected increase in visual impairment of 65% (5.3 million) women over the age of 40 by 2032. According to the Centers for Disease Control and Prevention, people most at risk for developing glaucoma typically belong to black, Hispanic, and Native American populations. By 2050, most glaucoma patients will be non-white, due primarily to the rapid increase in Hispanic glaucoma patients. By 2050, blacks and Hispanics will each constitute about 20% of all glaucoma patients.

In children, white children and children from families with higher incomes are more likely to have a detected, diagnosed, and treated eye condition, which suggests higher access to diagnostic care. Data from the 2016-2017 National Health Interview Survey indicates that Hispanic children (58.6%) were less likely to have ever had their vision tested compared to white children (65.4%). The COVID-19 pandemic has exposed where issues of health inequity exist in children due to social and environmental factors that place them at risk of entering a cycle of negative health outcomes and related outcomes on educational attainment, economic circumstances, and quality of life.

Policy Outlook and Positioning:

The COVID-19 pandemic has highlighted and renewed interest in addressing the significant gaps across racial and ethnic populations in access to health coverage. rates of chronic disease, and lower socioeconomic

status as compared to white or higher socioeconomic populations. Health equity has become a major theme in health policy and, while it will likely shape health policies that come out of the 117th Congress and the Biden Administration, achieving health equity will take time. One area that policymakers can start—particularly as the COVID-19 vaccine is being distributed—is to invest in a community-based health service infrastructure (including workforce), improved data collection efforts that incorporate population and demographic information as well as non-health related information like household income, attained education, and primary language, and issuing evidence-based guidance and awareness materials in a variety of languages.

Because health equity is such a vast topic that affects a number of national health policies and programs, legislation and regulatory policies that seek to address health inequity across populations and subgroups may be introduced or integrated on a program-by-program or issue-by-issue basis, requiring foresight of whether various legislative and regulatory proposals will improve or harm vision and eye health equity. Numerous issue-based thought leaders will attempt to define health equity as a matter of informing policy movements. It will be critical for Prevent Blindness to elevate the reality of disparate equity in vision and eye health by identifying existing and new advocacy partners to work together on legislation, appropriations, and rulemaking to ensure that vision and eye health plays an early role in shaping national policy on health equity.

Prevent Blindness Advocacy:

Prevent Blindness: Future of Vision: Forecasting the Prevalence and Costs of Vision Problems

Social Determinants of Health:

Many of the circumstances that contribute to vision loss or eye disease are as the result of both health and non-health

> related factors, requiring policy approaches to consider how

Addressing social determinants of health is a population health approach to vision and eye health.

factors external to health or "social determinants of health" may contribute to individual and community health status. Social and economic conditions including housing. employment status, income level, ability to access or afford healthy foods, and education level can all impact how an individual accesses care as well as the health of their community. Addressing social determinants of health

is a population health approach to vision and eye health as it allows for the opportunity to factor individuals' ability to access and afford care, encourage innovations at the community level in early detection and intervention approaches that connect high-risk patients to care, and can foster greater understanding of the barriers that prevent patients from accessing care.

Policy Outlook and Positioning:

Social determinants of health are increasingly receiving bipartisan support and attention, particularly given that the COVID-19 pandemic greatly illuminated how one's social conditions increase personal risk for not only catching the coronavirus but suffering its serious consequences. The opportunity for vision and eye health in addressing social determinants of health is significant as populations along racial and ethnic lines, aging adults, and even children are at increased risk of having

eye disease or chronic illnesses (such as diabetes or heart disease) that could lead to vision loss.

In 2020, Prevent Blindness endorsed legislation, H.R. 6561/S. 4440, the Improving Social Determinants of Health Act of 2020, led by the Trust for America's Health to coordinate efforts addressing social determinants of health across the Centers for Disease Control and Prevention. The House also passed legislation that included \$10 million to address social determinants of health in FY2021; however, the final FY2021 legislation (H.R. 4004/S. 2986, the Social Determinants Accelerator Act of 2019) included \$3 million to establish a social determinants of health pilot program that will include competitive grant funding opportunities to support "Social Determinant of Health Accelerator Plans" at state, local, or tribal levels. The 117th Congress is planning to reintroduce the Improving Social Determinants of Health Act.

Prevent Blindness Advocacy:

Prevent Blindness endorses legislation to address social determinants of health

Rural Health and Health Shortage Areas:

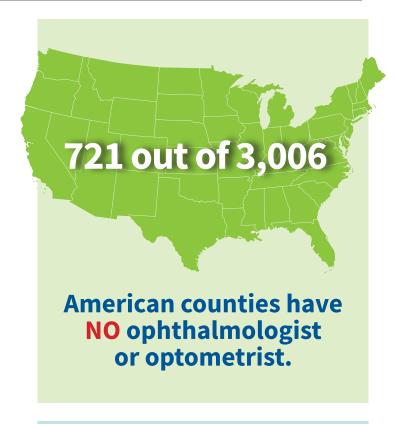
Many Americans live in areas of the country that are considered to be rural, underserved, or a health shortage area. According to federal guidelines through the Health Resources and Services Administration, there are only a certain number of providers available to serve a designated population figure. Current data indicates that 24% (721) of 3,006 American counties have no ophthalmologist or optometrist. The National Rural Health Association estimates approximately onefifth of the nation's population lives in rural America with only 10% of the country's physicians practicing in rural communities. For patients, this means that a needed or failed preventive vision screening or presence of a chronic illness may require them to travel—which means time away from work or home responsibilities, added costs, and difficulty with appointment availability—to

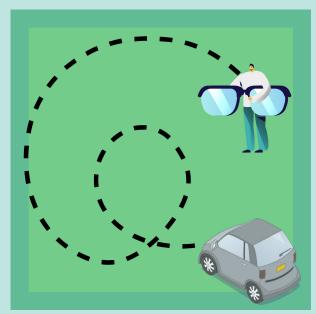
seek the level of care required to ensure they maintain their vision health. Adding these additional burdens to a patient makes adherence to care very difficult, in some cases, and could lead to worsened eye health and potentially loss of vision. In addition, population demographics of rural areas tend to be older adults at risk or living with chronic illness.

Clinical interventions, such as those in primary care settings and in community health centers, are especially critical for rural and health shortage areas; however, federal policy needs to create incentives that drive qualified providers to serve in rural and underserved areas, equip communities with appropriate infrastructure such as broadband to support communications, extend appropriate telehealth flexibilities, and stabilize community health facilities (such as federally-qualified health centers, critical access hospitals, and community health centers), and expand the community and public health workforce with supportive mechanisms that promote early detection, prevention, health promotion, and disease state monitoring. For many underserved and low-income communities, federally funded community and rural health centers may be the only source of eye and vision care services.

Policy Outlook and Positioning:

Rural and underserved population health is gaining bipartisan attention, particularly due to the economic impacts to communities and states when local or regional hospitals and health facilities close. Additionally, the coronavirus pandemic has led to a rapid proliferation of telehealth policies that has drawn attention to how technology can complement in-person care while ensuring patients can still access needed specialty and emergent care in their communities. As the 117th Congress reviews policies to improve rural health access, Prevent Blindness will partner with organizations that can leverage the expertise of vision and eye health providers and provide guidance on the best implementation strategy in the community health setting.





For many underserved, lowincome, and rural communities, federally funded community and rural health centers may be the only source of eye and vision care services.

PUBLIC HEALTH SYSTEMS OF CARE

Prevent Blindness promotes equitable access to vision and eye health for all Americans, regardless of age, racial and ethnic background, or socioeconomic circumstances. Public opinion polls conducted over the last 40 years indicate that Americans consistently fear losing their vision—a fear that is second only to fear of receiving a cancer diagnosis. Yet, vision and eye health are often an afterthought until changes to eyesight become noticeable and lost vision is permanent and irreversible. This is happening far too often as Americans struggle to access quality eye care and treatments; thus, a systems-level approach is necessary to ensure that all Americans can access vision and eye health information, assessment, and treatment.

A systems-level approach to vision and eye health includes numerous components that, when employed together, can help reduce the burden of vision and eye health on individuals and communities. Surveillance is necessary to assess the number of people affected, determine where the need is, and understand the demographics of the population impacted. Public health screenings and eye examinations employed together are complementary approaches to assessing eye problems; they are not competing health strategies. Public health screenings (provided they employ methods that are proven to detect vision problems and eye diseases and include a verifiable connection to follow-up eye care) that are offered in community settings create access points for care and promote early detection in high risk and underserved populations. Public education and awareness campaigns designed to prevent disease, inform the public of modifiable and unmodifiable risk factors, and promote healthful behaviors are essential in motivating individuals to seek care and drive demand for services from state and community leaders, who may engage multiple community, private sector, and nongovernmental stakeholders to partner on meeting this demand.

Vision and Eye Health Surveillance:

Vision and eve health is a necessary public health priority as 75% of incidents of vision loss can be prevented through early detection and timely treatment. Despite this high rate of preventability, the CDC estimates that, by 2050, incidence of diabetes-related eye disease, cataracts, agerelated macular degeneration, glaucoma, and vision impairment and blindness will face drastic increases without intervention; thus, making surveillance a crucial tool for developing interventions that can stem this escalating problem.

Due to chronic underfunding of our national public health system, our best-known national estimates of vision loss and eye disease is

15+ years old.

The Vision Health Initiative (VHI) at the Centers for Disease Control and Prevention tracks state-level data on vision loss and eye disease, evaluates variances across subgroups and demographics, and implements findings into evidence-based, strategic public health interventions at the state and community level. Due to a lack of adequate resources allocated through the federal appropriations process as a result of the 2011 Budget Control Act (a.k.a., sequestration, which established sharp agency-wide decreases in federal spending), the CDC has been unable to employ reliable surveillance activities since 2005 - 2008. Unfortunately, our bestknown estimate of our national vision loss and eye disease burden is almost 15 years old with current state and community interventions based on data that dates as far back as 1999.

Surveillance

Public Health Screenings

Public and Professional Awareness and Education **Policy and Practice Improvements**



Systems of Care

In 2020, Prevent **Blindness coalesced** 83 organizations across the vision and eye health community to **advocate Congress** for a \$5 million increase to the **CDC's Vision Health Initiative.**

In its 2016 report, Making Vision a Population Health Imperative: Vision for Tomorrow, the National Academies of Sciences. Engineering, and Medicine specifically names the CDC as vital to facilitating needed surveillance, public health research and interventions, and building state and local capacity to address vision and eve health at the community level. Building systems of care based on data that predates such trends as our rapidly

aging population, skyrocketing rates of chronic disease, new stresses to our eye health such as technology and digital device use, and rising costs of health care will only ensure that vision loss and eye disease remains on the margins of important national health care priorities.

Policy Outlook and Advocacy:

Securing increases to the CDC's VHI through the annual federal appropriations process is a top advocacy priority for Prevent Blindness, and a key feature of our annual Eyes on Capitol Hill advocacy agenda. Increasing federal spending on non-defense programs, which includes federal public health spending, has met several budgetary challenges in FY20 and FY21. In order to avoid the sharp decreases in agency spending as mandated by budget sequestration, Congress had to agree on legislation every 2 years to bypass sequestration with spending limits (called caps) for all defense and nondefense programs. While the caps established for FY20 and FY21 in the Bipartisan Budget Act of 2019 were higher than the caps mandated under sequestration, the allocation for non-defense spending was lower than needed to increase public health program spending.

In 2020, Prevent Blindness led a coalition of 83 vision and eye health organizations in sending a letter to House and Senate appropriators, and launched an online grassroots advocacy campaign urging these investments in FY2021. Despite these important efforts, vision and eye health programs at the CDC have remained flatfunded at a total of \$5 million since FY18—including in the FY21 final legislation. In its FY20 appropriations bill, the House recommended a double increased from \$1 million to \$2 million. While this increase was not finalized in the FY20 spending law, the increase signals that lawmakers are gradually beginning to recognize the need to reinvest in vision and eye health.

The federal budget and appropriations cycle, which as of recent years has become a highly unpredictable and overcomplicated process, begins in February 2021. However, as is typical with a new Administration, President Biden is not likely to release his budget (including proposed funding for the CDC) until the late spring of 2021. The President's budget, which is a policy document that establishes Administration priorities for federal spending but does not carry the weight of law, often sets the pace for the appropriations process in Congress. The 117th Congress is likely to continue efforts to respond to the COVID-19 pandemic through the appropriations process. It is unclear how

a closely divided House and Senate will respond to these additional relief efforts, particularly as some lawmakers may have concern over ballooning deficits.

As part of our advocacy to secure longoverdue investments to the CDC's vision and eye health programs, Prevent Blindness will continue to work in lockstep with coalitions such as the CDC Coalition and the Coalition for Health Funding to secure high agency-level increases to the CDC as well as high top-line spending figures for nondefense discretionary spending and programs

Surveillance is a matter of good governance as updated and reliable data facilitates efficiency in limited resources by directing them to where they are needed most, fosters innovation and partnerships that reflect populationlevel needs, and establishes objectives based on measurable outcomes.

funded under the Labor-HHS-Education spending bills. Prevent Blindness has also taken the opportunity to elevate the need for vision and eye health surveillance for both children and adults—as part of policy efforts to implement lessons learned in the COVID-19 pandemic.

Prevent Blindness Advocacy:

Prevent Blindness leads 83 vision and eye health organizations asking Congress to fund CDC's Vision and Eye Health programs; Prevent Blindness testimony to House Labor-HHS-Education Appropriations Subcommittee; Improving Vision and Eye Health at the CDC; CDC Coalition letter for FY21 appropriations; CDC Coalition letter for FY20 appropriations

Vision and Eye Health Surveillance System (VEHSS):

Surveillance is a core public health function that assesses and tracks population risk factors for vision loss and eye disease, establishes priorities and objectives for intervention, and evaluates the effectiveness of resources on meeting objectives. Surveillance can also be used to collect data around the attributes of vision loss and eye disease, such as means of access to care, education and income levels, racial and ethnic background, rural or urban location, age, gender, and other population-level factors.

A national surveillance system for vision and eye health—such as the Vision and Eye Health Surveillance System (VEHSS) at the Centers for Disease Control and Prevention—that incorporates data from multiple sources contributes to a national overview of the burden of vision impairment and eye disease and provides scope and depth needed to determine the burden and need across

a number of social, economic, racial, age, and gender groups. Ultimately, this allows for the interdisciplinary use of information to create targeted approaches for the public and allows the vision and eye health community to be more responsive to shifting eye health needs.

Policy Outlook and Positioning:

National forecasts estimate that expenditures on vision problems, due to an aging population and changes in demographics, will reach \$385 billion by 2032 and \$717 billion by 2050. The proportion of these costs paid by government programs will increase from 32.6% to 41.14% by 2050. Therefore, surveillance is a matter of good governance as updated and reliable data directs limited resources to where they are needed most, fosters innovation and partnerships that reflect population-level needs, and structures objectives based on measurable outcomes.

Continuing our advocacy to equip the Vision Health Initiative is essential to meet the need for reliable surveillance data using the most reliable surveillance tool available: the National Health and Nutrition Examination Survey (NHANES). With the right resource allocation, the CDC can conduct long overdue and needed national surveillance to determine rates of vision and eye examinations and measurements of visual acuity, screening tests, and visual functioning assessment to better determine where gaps in access and patient education exist. The CDC can also use this updated data to integrate into the existing Vision and Eye Health Surveillance System. With this data, state and local public health departments and community leaders can respond to the needs of their populations with collaborative interventions and targeted strategies to improve vision and eye health at the state, local, or systems level.



THE VISION AND EYE HEALTH SURVEILLANCE SYSTEM

A national data system for vision and eye health

Public Health Data and Infrastructure:

Vision and eye health are not immune from inadequacies and inefficiencies in our national public health system and, in many cases, remains disadvantaged by outdated public health data processes and infrastructure.

Public health officials and lawmakers are increasingly realizing that our national public health data and infrastructure is woefully inadequate to stay ahead of and respond to emergency outbreaks, public health emergencies, and effectively manage chronic disease efforts. Currently, our national public infrastructure includes manual processes like paper records, spreadsheets, faxes, and phone

calls, lack of interoperability, reporting inconsistency, fractured data standards which leads to errors in quality, timeliness, and communication, and data systems that are subject to cybersecurity threats and lack adequate security to integrate health data. Vision and eye health are not immune from inadequacies and inefficiencies in our national public health system and, in many cases, remains disadvantaged by outdated public health data processes and infrastructure.

Policy Outlook and Positioning:

In 2019 and 2020, a collaborative advocacy effortthe "Data is Elemental to Health" campaign led by the Council of State and Territorial Epidemiologists across the public health community to direct federal resources towards public health data and infrastructure commenced with House and Senate appropriators. As part of a community-wide effort to modernize our national public health infrastructure, advocacy focused on promoting a five-pronged approach to a capable American data system and public health surveillance enterprise, including: the National Notifiable Disease Surveillance System, electronic case reporting, syndromic surveillance, an electronic vital records

system, and laboratory information systems. The advocacy efforts also include a public health data workforce component to enable public health scientists and practitioners to successfully administer new processes and respond to security threats. These efforts are projected to need a \$1 billion investment over 10 years to the Centers for Disease Control and Prevention. The FY20 appropriations legislation included \$50 million in new funds for data modernization.

Prevent Blindness Advocacy:

Public health community recommends \$4.5 billion to modernize public health infrastructure; Data is Elemental to Health Letter to Congressional appropriators

Public Health Workforce:

A capable public health workforce is essential to achieving a systems-wide approach to vision and eye health. In order to offer needed eye care to individuals and populations, the necessary eye care providers and ancillary staffing must be in the right places and willing to see those who need care. Currently, concerns remain about the distribution of providers and the willingness of providers to participate with private or public insurers that provide insufficient reimbursement. In the vision and eye health community, eye care provider distribution and lack of availability enhances concerns that staying ahead of trends such as aging and eye disease from chronic conditions will go unchecked. The public health profession has, however, been on the decline since the 2008 recession and has not adequately recovered unlike other areas in the public sector workforce. Without addressing new and emerging challenges to the public health workforce such as an obsolete national public health infrastructure, security threats, and declining public trust, the public health workforce will continue its decline and bring vision and eye health goals with it.

Policy Outlook and Positioning:

The coronavirus pandemic has complicated public health workforce policy goals as a result of diminished public trust in the government's public health roles

and functions. Overcoming this new distrust will take time, but the role of public health professionals and practitioners is evermore important. Therefore, a strategy of "leaning into" the opportunity present within this significant challenge and highlighting the benefits of a strong, capable public health workforce is necessary to overcome public distrust. The responsibility in achieving public health workforce goals is not singular to Prevent Blindness and will require coalescing with stakeholders across public health to accomplish broad goals that have downstream impacts on vision and eye health.

Expanding the definitions of "underserved areas," and "healthcare professional shortage areas (HPSA)," or expanding the list of providers who qualify for loan repayment under the NHSC is a difficult achievement. The NHSC, in particular, faces frequent reauthorization battles in Congress, which typically considers how to expand funding to areas that already qualify for funding under current program definitions. Additionally, any funding increases to the NHSC are typically designed to respond to emerging threats like the opioid crisis or mental and behavioral health challenges.

As part of this effort, Prevent Blindness joined the Public Health Workforce Coalition through the National Association of City and County Health Officials (NACCHO) in 2020 whose work complements the public health workforce component included in the "Data is Elemental to Health" campaign to modernize our national public health infrastructure. The Public Health Workforce Coalition includes the component of advocating Congress to enact a loan

repayment program for public health professionals who serve 2 years in a local, state, or tribal health department. This advocacy request is modeled after the National Health Service Corps (NHSC), which currently does not include eye care practitioners, such as optometrists, general practice ophthalmologists, or other primary eye care providers who specifically serve in underserved areas or underserved populations.

Without addressing new and emerging challenges such as an obsolete national public health infrastructure, security threats, and declining public trust, the public health workforce will continue its decline and bring vision and eye

health goals with it.

The challenge and opportunity for the vision and eye health community in succeeding in goals to integrate eve care providers into the NHSC or other public health workforce advocacy is to promote the benefits of a systems-level approach to

care and integrating vision and eve health into current and existing disease prevention and health promotion interventions.

Prevent Blindness Advocacy:

Prevent Blindness joins Public Health Workforce Coalition

INNOVATIONS IN VISION AND EYE HEALTH TREATMENTS: DEVELOPMENT, DISTRIBUTION, AND ACCESSIBILITY

Pharmaceuticals are a key part of the treatment plan for many eye diseases, including rare diseases that cause vision loss, and their ongoing availability, affordability, and accessibility requires long-term planning. Federal policy has a number of powerful mechanisms to promote a continuum of research to innovation to market acquisition and patient access, including investment in biomedical research, to regulations ensuring safety and efficacy, to affordable coverage in insurance programs.

Patient assistance programs provide a muchneeded safety net in both commercial and publiclyfunded health plans for patients who cannot afford the burgeoning costs of their treatments. As well, treatment decisions should be made the patient and their eye care provider, and treatment options must be accessible. affordable, and safe for patients.

While the drug access and reimbursement systems are complex and built on an underlying system that is equally complex and difficult to navigate, patients should have some "skin in the game" and personal responsibility when it comes to managing their health and adhering to their treatment. Accordingly, policies must strive to ensure patients are well-informed consumers and promote patient decision-making. The total cost of care and aggregate impact on all patients, families, payers, and caregivers should also remain at the center of the conversation to ensure the burden doesn't fall disproportionately on one entity within the system, including patients and families.

Affordability and Accessibility of Drugs and Treatments:

Affordable and accessible drugs and treatments are a vital component to a patient's treatment plan to stopping eye disease from progressing. Increasingly, drugs and treatments are becoming inaccessible to patients who may not have adequate coverage, may have a number of conditions to prioritize in addition to preventing

vision loss, or may have difficulty accessing specialty eye care due to lack of transportation or being located in a health care shortage area. Additionally, patients may not have understandable and actionable information about their treatment options, including costsharing, to not only access their treatment but adhere to it. Patients who may not understand how their eve care needs will be balanced against coverage policies may be deterred from seeking eye care altogether, thus furthering their risk for permanent vision loss

Policy Outlook and Positioning:

Lowering the costs of prescription drugs for patients and also to the health care system was a major theme for the 116th Congress and the Trump Administration; however,



As an organization that promotes equitable access to vision and eye care treatment,

Prevent Blindness believes that out-ofpocket costs should not prevent people from accessing the treatments and medications they need to protect their sight and slow the progression of blinding eye diseases.

there was very little agreement on the correct approach. Several legislative approaches introduced in the House and the Senate focused on areas such as increasing competition by introducing more generic drugs to the market, reducing patient expenses by establishing caps on out-of-pocket spending and utilizing rebates at the point of sale, and disclosing costs to patients as a manner of achieving market transparency and empowering patient decision-making among many other proposals. In addition, addressing the costs of drugs

Step therapy and prior authorization may **put the patient** at risk for vision *loss* due to treatment delays, additional doctor visits, and use of the insurance pre-approval process (which comes with added administrative cost) that could potentially be avoided if the patient had access to treatment prescribed by a qualified provider in the first place.

under the Medicare Part D program has met policy differences between instilling a cap on out-ofpocket costs or annual limits. As an organization that promotes equitable access to vision and eve care treatment, Prevent Blindness believes that out-of-pocket costs should not prevent people from accessing the treatments and medications they need to protect their sight and slow the progression of blinding eve diseases. We also believe that costs should allow, not prevent, patients to remain on their prescribed course of treatment as long as their providers indicate is necessary. Should the 117th Congress once again take up efforts to lower the costs of prescription drugs on consumers and the health care system,

Prevent Blindness will encourage policies that promote consumer choice while mitigating over-utilization and over-consumption, and balance provider behavior with appropriate oversight mechanisms on purchasers, payers, manufacturers, and other players in the marketplace to ensure the responsibility to lower cost and improve access falls on all stakeholders.

Utilization Management: Step Therapy and Prior Authorization:

"Fail first" policies, also known as step therapy, are policies employed by insurance companies to manage beneficiary utilization of expensive drugs and control

costs by requiring that patients first try the cheapest covered drug, regardless of its effectiveness in treating a condition, rather than the medicine or treatment originally prescribed or preferred by the doctor. Under step therapy, patients may be required to seek authorization from their insurance provider before starting a course of treatment or may learn after their doctor has prescribed the treatment that their insurance company is requiring them to try a cheaper, potentially less effective drug than was prescribed first. Before having access to the treatment prescribed by their provider, the patient would need to first demonstrate that the drug isn't working before their insurance will cover a more expensive and possibly more effective treatment.

Utilization management policies like step therapy and prior authorization pose incredible risks to patients who may not have the luxury of time to try ineffective treatments as they are facing progressive vision loss from eye diseases like age-related macular degeneration. Vision loss, once it occurs, cannot be reversed; thus, making time of critical essence in treating the condition before it gets worse. In addition, step therapy and prior authorization may put the patient at risk of treatment delays, additional doctor visits, and use of the insurance pre-approval process (which comes with added administrative cost) that could potentially be avoided if the patient had access to treatment prescribed by a qualified provider in the first place.

Policy Outlook and Positioning:

Prevent Blindness values the patient/doctor relationship and the need for patient choice in making their own treatment decisions with their provider that are in the best interest of patient health. While we understand that controlling health care costs is an important and necessary conversation, Prevent Blindness affirms that relying on a step therapy policy places an undue hardship on patients who are facing advancing loss of vision and may not have the luxury of time to try multiple treatments before losing their sight.

Step therapy and prior authorization does not only affect the vision and eye health community. Patients who face other complex conditions that require other specialty care also face the devastating consequences

of utilization management policies, which makes a powerful constituency to advocate against these harmful policies. As such, Prevent Blindness works through coalitions such as the Part B Access for Seniors and Physicians (ASP) Coalition to advocate for the reversal of step therapy and prior authorization policies to Congress and the Administration. As part of these efforts, Prevent Blindness endorsed H.R. 3107, the Improving Seniors' Timely Access to Care Act of 2019, which would create a "real-time" electronic prior authorization process. require insurance plans to adopt prior authorization policies that adhere to clinically-based guidelines and promote continuity of care, provide rationale for denials and establish accountability mechanisms for plans to make timely decisions, and prohibit step therapy or prior authorization on medically-necessary services utilized during surgical or interventional procedures. While this legislation did not pass the 116th Congress, many policies encouraging step therapy and prior authorization still exist as a result of actions taken by the Trump Administration to allow for its use on Part B drugs in Medicare Advantage programs.

Prevent Blindness Advocacy:

Prevent Blindness letter to CMS regarding step therapy on Part B drugs; ASP Coalition letter urging reversal of prior authorization policies on Part B drugs in Medicare Advantage; Prevent Blindness joins over 395 organizations to endorse prior authorization legislation

Drug Pricing Reforms:

The high price of prescription drugs can often pose the greatest barrier in access to sight-saving therapies and treatments to manage chronic conditions. When patients cannot afford their therapies, they cannot be adherent to their treatment plans, which can increase total costs for these patients over time. Patients who face a future of progressive sight loss due to blinding eye diseases who are unable to access or afford treatment may be at risk of other conditions such as cognitive decline, social isolation and loneliness that could lead to or exacerbate mental health, as well as risk of disabling injury or even death due to a heightened likelihood of experiencing a fall.

Policy Outlook and Positioning:

While most lawmakers on both sides of the aisle have raised concerns about drug prices, policy disagreements across party lines have slowed progress towards a bipartisan agreement. Members of Congress from each party pushed their own drug pricing legislation separately, with the need to cap out-of-pocket costs on Part D drugs emerging as an area of relative bipartisan agreement. A legislative proposal, which was part of a Senate Finance Committee package, sought to tackle

The Centers for Medicare and Medicaid Services (CMS) has indicated that the Most **Favored Nations** model would force beneficiaries to "forego" care; in fact, the CMS Office of the Actuary predicts 19% lower utilization of drugs due to patients having "no access" at all to treatments.

the high costs of Part B drugs by tying manufacturer rebates to inflation; however, it did not achieve final passage in the Senate. A House Democratic proposal, which was not considered by the Senate, included a provision to tie the price of certain Part B drugs to international pricing (which would result in savings that would create a Medicare vision benefit); however, expanding these benefits would be extremely difficult if the drug pricing negotiation proposals are removed.

After drug pricing efforts failed to advance in the Senate, the Trump Administration pursued a nationwide demonstration model that would tie the price of certain expensive Part B drugs to the "most favored nations" (MFN) economic indicator. The MFN rule would base the purchase price for 50 injectable drugs—which includes treatments for age-related macular degenerationpayable under the Medicare Part B program (treatments that require a physician to administer) on the lowest cost paid by economically-similar countries in an effort to reduce overall costs to the Medicare program. The Centers for Medicare and Medicaid Services (CMS) has indicated that the model would force beneficiaries to "forego" care; in fact, the CMS Office of the Actuary

predicts 19 percent lower utilization of these drugs due to patients having "no access" to these treatments.

Prevent Blindness has serious concerns with proposals that seek to lower the costs of prescription drugs to international price indexes, and has engaged in numerous advocacy efforts to delay or prevent its implementation until stakeholders can be thoroughly engaged in the process of providing input. Through the Part B Access for Seniors and Physicians Coalition, we advocated to House and Senate leadership to delay implementation of the MFN model and worked with partners in the vision and eye health community to establish a grassroots advocacy campaign to urge patients to notify Congress about the potentially harmful impacts on their ability to access sight-saving treatments.

Prevent Blindness Advocacy:

Prevent Blindness Statement Opposing Most Favored Nations Policy; Prevent Blindness Statement Opposing Executive Orders on Drug Pricing; Prevent Blindness Statement on H.R. 3

Research and Development:

Prevent Blindness encourages policies that address translational research and are incorporated into a public health strategy, including surveillance and prevention.

The National Eye Institute (NEI) at the National Institutes of Health (NIH) is the premier federal research agency for vision and eye health. Since 2003, the NEI has not been funded at a level that adequately retains its purchasing power; meaning, research often comes at the expense of the NEI's administrative. operational costs. The NIH, including the NEI and its 26 additional research institutes, have enjoyed steady federal increases

over the last several fiscal years. Since FY2018, the NEI's budget has been increased from \$797 million to \$835 million in FY2021. Even with these steady increases, the total purchasing power of the NIH is still 13% below FY2003 levels.

Policy Outlook and Positioning:

The 117th Congress can be expected to continue the trend of increasing NIH funding for at least the next two fiscal years. As Vice President, Joe Biden was a leading advocate for health research, having taken a leading role in the efforts to pass the 21st Century Cures Act, along with launching the precision-medicine-focused cancer moonshot.

Prevent Blindness is a a member of both the National Alliance for Eye and Vision Research and the Alliance for Eye and Vision Research, which collectively inform and advocate lawmakers for increased funding to the NEI. Prevent Blindness has sought to encourage the NEI to improve our national vision and eye health through research that generates more evidence-based screening protocols and to ensure that treatments are available, safe, and effective. As part of our advocacy to improve vision and eye health on the population level, Prevent Blindness encourages policies that address translational research and are incorporated into a public health strategy, including surveillance and prevention. Robust funding levels for the NEI as well as coordination with key federal partners will strengthen basic and clinical research and ensure that patients ultimately benefit from promising innovations.

Promoting Diversity in Clinical Trials:

Innovations in eye care and treatment are rapidly emerging and becoming increasingly available to patients. However, a one-size approach to rigorous testing of these new treatments is no longer the best method of ensuring treatments are safe, effective, and accessible to patients. Researchers are increasingly becoming attuned to factoring in the patient perspective in clinical trials as well as the patient's attributes, including racial and ethnic background, socioeconomic

circumstances, and gender. Patient groups are also requesting that patient considerations are factored into the clinical trials process to ensure that patient needs including means of accessing treatments, preferences for treatment, personal community and support system, and quality of life and life satisfaction—are addressed on the front end of designing treatments and therapies.

Policy Outlook and Positioning:

The FDA recently released final guidance on "Enhancing the Diversity of Clinical Trial Populations" which notes that "failure to include complex participants in a development program may lead to a failure to discover important safety information about use of the investigational drug in patients who will take the drug after approval." Prevent Blindness is also encouraged by the steps taken through the FDA to promote patientfocused drug development, and will explore ways to incorporate the patient voice in drug development and evaluation.

Moving forward, Prevent Blindness will look for opportunities to work with FDA to encourage broad population participants in its clinical trial phases as well as train patient advocates on the phases of clinical trials, the avenues for involvement, and the importance of diverse representation. Additionally, our work will closely follow that of the National Health Council-also a proponent of diversifying populations in clinical trials—to implement the FDA's policies.



GLOBAL VISION AND EYE HEALTH

While Prevent Blindness's work generally focuses on improving access to vision and eye health care domestically, numerous efforts to achieve vision and eye health on the global stage through the efforts of international, health-oriented convening bodies and nongovernmental organizations can inform and offer solutions in the United States.

Prevent Blindness partners with organizations such as the International Agency for the Prevention of Blindness (IAPB) to raise the profile of policies, practices, and projections-such as the IAPB Vision Atlas-to Members of Congress and the Executive Branch through events such as World Sight Day. Efforts from internationally-focused stakeholders can help inform any efforts with convening organizations like the United Nations, whose sustainable development growth (SDG) goals may include vision. Additionally, a 2019 World Health Organization report on vision offers potential solutions for the global vision and eye community to implement that underscore the need for vision to be elevated as a means to unlock human potential around the world.

Policy Outlook and Positioning:

Efforts on the global stage to prioritize vision and eye health will likely be backstage due to the coronavirus pandemic; however, the expectation of several reports from well-respect organizations expected in early 2021 will continue to explore the need globally.

Prevent Blindness Advocacy:

World Health Organization 2019 "World Report on Vision"; United Nations Sustainable Development **Goals 2019**







