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U.S. Population and Vision Health in 2020 and Beyond

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National Eye Institute, NIH

NEI Strategic Planning: 2020 Vision for the Future

Focus on Eye Health National Summit | An Eye to the Future
2020 Vision for the Future

NEI Strategic Planning Process

Prevent Blindness Summit—July 15, 2020
NEI has a long history of program planning

1973
1978
1983
1988
1994
1999
2004
2012

1) Retina Diseases
2) Cornea Diseases
3) Lens and Cataract
4) Glaucoma and Optic Neuropathies
5) Strabismus, Amblyopia and Visual Processing
6) Low Vision/ Blindness Rehabilitation
Areas of Emphasis

Visual System in Health and Disease
- From Genes to Disease Mechanisms
- Biology and Neuroscience of Vision
- Immune System & Eye Health

Capitalizing on Emerging Fields
- Regenerative Medicine
- Data Science

Preventing Vision Loss and Enhancing Well-Being
- Individual Quality of Life
- Public Health & Disparities Research
Request for Information

- What are the most significant **scientific discoveries** in vision research since 2012?
- What **new opportunities** have been enabled by scientific discoveries or technology development?
- What **needs and gaps** in research, health, and quality-of-life should be addressed by the NEI?
Request for Information

- **Dates:** Nov 15, 2019 – Jan 9, 2020
- **Format:** Web form on NEI Homepage
- **Broadcast:** NIH Guide
  - Federal Register
  - Email to NEI Grantees
  - NEHEP Distribution List: 64 partners (ARVO, AOA, AAO)
  - Stakeholder distribution lists (AEVR, APHA)
- **Responses:** 252
RFI Respondents by Sector/Affiliation

- Parents/Citizen Advocates: 55, 54, 49
- Academics: 29, 25, 15, 13, 11
- Teachers/Specialists/Schools for Blind or Visually Impaired: 1
- Clinicians/Medical Professionals: 1
- General Public: 1
- Society/Associations: 1
- Government: 1
- Industry: 1

NUMBER OF COMMENTS (N=252)
*Responses that addressed different areas of emphasis were counted multiple times.*
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^ Not included are 25 comments that did not fall under any areas of emphasis.
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Incorporating RFI Feedback

- **CVI**: Panelists in Neuroscience and Rehabilitation, including educators for the blind; CVI screening tools, diagnostic code, patient registry
- **Genes**: Gene therapy (next generation tools; multigenic conditions), different animal models
- **Neuroscience**: Behavioral neuroscience; visual attention in CVI
- **Immunology**: Host immune factors in chronic disease; microbiome
- **Regen Med**: Exosomes; trabecular meshwork stem cells; organoids
- **Data Science**: Apply AI to multi-modal data; automated screening; AI ethics
- **Individual QOL**: Social Isolation/ depression; cognitive tests in eye exams; telemedicine and technology expertise on panel
- **Public Health/Disparities**: Health services research on therapy effectiveness in populations; behavioral science; vision care deserts; causes of increased myopia; health economics; diverse populations
From Genes to Disease Mechanisms

Vasilis Vasiliou, PhD (Co-Chair)
Renu Kowluru, PhD, FARVO (Co-Chair)
Louis Pasquale, MD, FARVO (NEI Council)
Ales Cvekl, PhD
Stephen Daiger, PhD
Elizabeth Engle, MD
Mike Hauser, PhD

Salil Lachke, PhD
Peter Lwigale, PhD
Patsy Nishina, PhD
Eric Pierce, MD, PhD
Stephen Tsang, MD, PhD
Christine Wildsoet, OD, PhD

NIH Staff: Grace Shen, PhD; Charles Wright, PhD; Nora Wong, MPH; Scott Henke, PhD; Nataliya Gordiwenko, PhD
From Genes to Disease Mechanisms

Panel Highlights (Preliminary)

- **Databases**—Standardized data collection to allow for harmonization with currently existing NIH-wide datasets
- **New model systems**—Centralized support for development of patient-derived iPSCs, organoids, cre-mouse lines, zebrafish lines
- **Aging**—Connect general mechanisms of aging processes and age-related eye diseases
- **Angiogenesis**—Compare blood vessel growth during tumor development versus retinal vascular diseases
- **Sex hormones**—Explore their role in eye disease
- **Redox biology**—Understand mechanisms in eye development and disease
- **Collaborations and talent pool**—Expand interactions beyond ophthalmology and vision research departments
Biology and Neuroscience of Vision

Panel Highlights (Preliminary)

- **BRAIN Initiative**—Apply new imaging technologies to better understand visual system
- **Visual circuit dissection**—Single cell RNASeq to catalog cell subtypes and gene programs, coupled with multicellular recording; 3D reconstruction of synapses
- **Molecular responses**—Probe development and pathogenesis with AAV, optogenetics, 2-photon tools
- **Plasticity**—Develop tools to modulate plasticity in development and repair
- **Cortical Visual Impairment (CVI)**—Develop functional assays to define and diagnose broad family of cortical visual impairments
- **Visual decision making**—Build on visual processing research to model higher level brain functions
Immune System and Eye Health

David Leib, PhD (Co-Chair)

Jennifer Thorne, MD, PhD (Co-Chair)

Russ Van Gelder, MD, PhD (NEI Council)

Dong Feng Chen, MD, PhD

Elisabeth Cohen, MD

Reza Dana, MD, MSc, MPH

Andrew Dick, MD

Thomas Ferguson, PhD

Phoebe Lin, MD, PhD

Dan Martin, MD

Jerry Niederkorn, PhD

H Nida Sen, MD, MHSc

Steven Yeh, MD

NIH Staff: Sangeeta Bhargava, PhD; Maria Disotaur, PhD; Shefa Gordon, PhD; George McKie, DVM, PhD; Charles Wright, PhD
Immune System & Eye Health

Panel Highlights (Preliminary)

- **Microbiome**—Role in regulating homeostasis; apply Artificial Intelligence for personalized medicine
- **Infectious eye disease**—(Herpes, Uveitis, Ebola, SARS-CoV-2) mechanisms
- **AMD/Chronic degenerative diseases**—Mechanisms how chronic diseases differ from inflammatory diseases
- **Immunotherapy**—consider acute/chronic, stimulating/regulatory responses
- **Alternative therapies to steroids** for uveitis
- **Immunosenescence**—Explore immune diseases of the aging eye and impact of immune environment
- **Functional mapping**—The role of different genes in immune pathways
- **Neuroimmunology and “immune privilege”**—Lessons learned from the brain: entry point of lymphocytes; resident CD8+ cells in meninges; beneficial impact of cytokines; effects of IFN-γ on neuron behavior
- **Live quantitative imaging** of ocular immune response
Regenerative Medicine

Maria Valeria Canto-Soler, PhD (Co-Chair)

Jeffrey Goldberg, MD, PhD (Co-Chair)

Katia Del Rio-Tsonis, PhD (NEI Council)

Marco A. Zarbin, MD, PhD, FACS (NEI Council)

Kapil Bharti, PhD

Constance Cepko, PhD

Mark Humayun, MD, PhD

Anna La Torre Villa, PhD

James G. Patton, PhD

Rajesh C. Rao, MD

Tom Reh, PhD

Mark Rosenblatt, MD, PhD, MBA

Krishanu Saha, PhD

NIH Staff: Lisa Neuhold, PhD; Maryann Redford, DDS, MPH; Amber Reed; Steven Becker, PhD; Maria Disotaur, PhD
Regenerative Medicine

Panel Highlights (Preliminary)

- **Human immune response**—Understand response to cell & tissue transplants under different disease conditions and surgical methods
- **Material transfer**—Understand and harness material transfer in photoreceptor precursors and extracellular vesicles from other cell types for therapeutic benefit
- **Automation and artificial intelligence**—Apply new technology to improve cell manufacturing capacity and quality
- **Direct reprogramming**—Support techniques to differentiate cells into other cell types using biological or chemical factors. (e.g., Convert Müller cells into rods, RPE into retinal neurons, rod photoreceptors into cones)
- **Retina organoids, extracellular vesicles, and biomaterials**—Leverage recent advances to enhance regenerative medicine strategies
Data Science

Michael Chiang, MD (Co-Chair)
Aaron Lee, MD, MSc (Co-Chair)
Dennis M. Levi, OD, PhD (NEI Council)
Farran Briggs, PhD, ScM
Eric Buckland, PhD
Jonathan Haines, PhD
Zhihong (Jewel) Hu, PhD

Elizabeth (Lizzy) Pike, JD, LLM
Marylyn Ritchie, PhD
Joel S. Schuman, MD
Ayellet Segrè, PhD
Sebastian Seung, PhD
Kaushal Solanki, PhD

NIH Staff: James Gao, PhD; Kerry Goetz, MS; Jerome Wujek, PhD; Paek-Gyu Lee, PhD; Jennifer Burrell
Data Science

Panel Highlights (Preliminary)

- **NIH Data Science Plan**—Determine NEI role within larger NIH Data Strategy framework

- **Big data**—Vision can lead innovation due to unique data types; access to clinical, imaging, genomic databases must address privacy concerns (PHI, PII), data sharing incentives, lack of standardization (de-identification of imaging data; storage and formats)

- **Artificial Intelligence**—Barriers include standardizing data and combining disparate data types

- **Computational advances**—Invest in developing good code and providing accompanying annotation; review process for methodology to avoid wasting good data collection; common data repository for large datasets

- **Training and Workforce**—Recruit and train new talent; code creation challenges (‘code-a-thons’)
  - **Centralized expertise**—Create distributed centers/cores of expertise available to collaborate with data creators
Individual Quality of Life

Ava Bittner, OD, PhD (Co-Chair)
Lotfi Merabet, OD, PhD, MPH (Co-Chair)
Mary Elizabeth Hartnett, MD (NEI Council)
Kim Avila, PhD
Audon Brunes, PhD
James Coughlan, PhD (NEI Council)

Gordon Legge, PhD
Susan Primo, OD, MPH
Penny Rosenblum, PhD
Joan Stelmack, OD, MPH
Bonnielin Swenor, PhD, MPH
Mark Wilkinson, OD

NIH Staff: Cheri Wiggs, PhD; Don Everett, MA; Rachel Bishop, MD, MPH
Individual Quality of Life

Panel Highlights (Preliminary)

- **Brain related visual impairment**—CVI, TBI, stroke, and neuroscience/neuroplasticity
- **Telehealth**—For eyecare and rehabilitation
- **Comorbidities**—Better understanding, optimal management
- **Mental health and wellness**—Screening, understanding, and treating; strategies to promote wellbeing
- **Technology and communications**—Improving efficient access to mobile-based applications, websites, and graphics
- **Rehabilitation**—Develop evidence-based practices
- **Navigator**—Explore use of a human (possibly telehealth) assistant to help individuals navigate resources
- **Education**—Identify predictors of academic success; establish importance of various educational tools
- **Employment**—Establish reliable statistics; identify predictors of success and barriers to employment
- **Driving and navigation**—Tools to promote independence
Public Health and Disparities Research

Susan Cotter, OD, MS (Co-Chair)
David Musch, PhD, MPH (Co-Chair)
Eduardo Alfonso, MD (NEI Council)
Megan Collins, MD
Adam Glassman, MS
Kirk Greenway, MA, MPH

Eve Higginbotham, SM, MD
Charlotte Joslin, OD, PhD
Janet Leasher, OD, MPH
David Lee, PhD
Kevin Stroupe, PhD
James Tsai, MD, MBA

NIH Staff: Jimmy Le, ScD; Nora Wong, MPH
Public Health & Disparities Research

Panel Highlights (Preliminary)

- **Improved and Up-to-date Epidemiological data**—Especially in pediatric and underserved populations
- **Behavioral economics**—Studies to generate evidence for the value of including vision health in population health policies
- **Cost-effectiveness research**—Demonstrate cost savings/improved health outcomes for interventions (low vision rehab), provisions (eye care to vulnerable populations), diagnostics (screening), technology and policy
- **Develop tools to increase access to care**—Telemedicine can be a good tool, but not everyone can benefit
- **Harmonized study designs and outcome measures**—Rigorous studies to improve systematic reviews, policies, and practices
- **Health behavior research and care delivery models**—Understand patient adherence and utilize available treatments or health services
- **Diversity of NEI-supported researchers**—New perspectives to lead and conduct epidemiologic, qualitative, and minority-focused research
- **Community engagement, social determinants of health, health literacy**—Strategies to better address underserved and minority populations
Timeline & Next Steps

- Council Mtg- Concept Review
- Request for Information
- Council Mtg- RFI Results
- Identify and confirm Panelists for each area
- Co-chair Kick-off meeting
- Panel discussions- Videoconference 1
- Panel discussions- Videoconference 2
- Panel discussions- Videoconference 3
- Council Mtg- Panel Reports
- Planning document- outline and template
- Draft planning narrative
- Panel review
- NEI Review
- Begin layout
- Council Review and Meeting
- Publish
Submit Your Questions Through Q&A