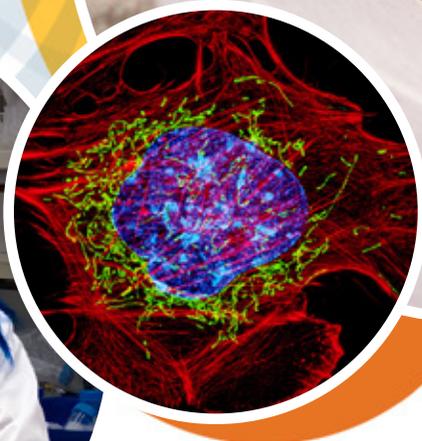
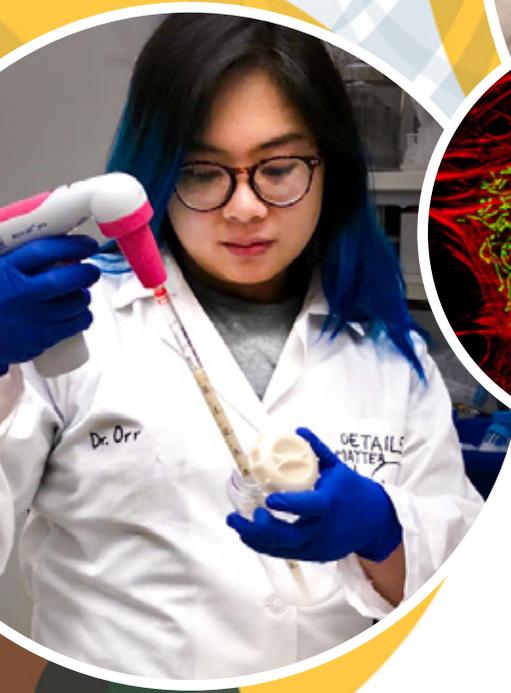


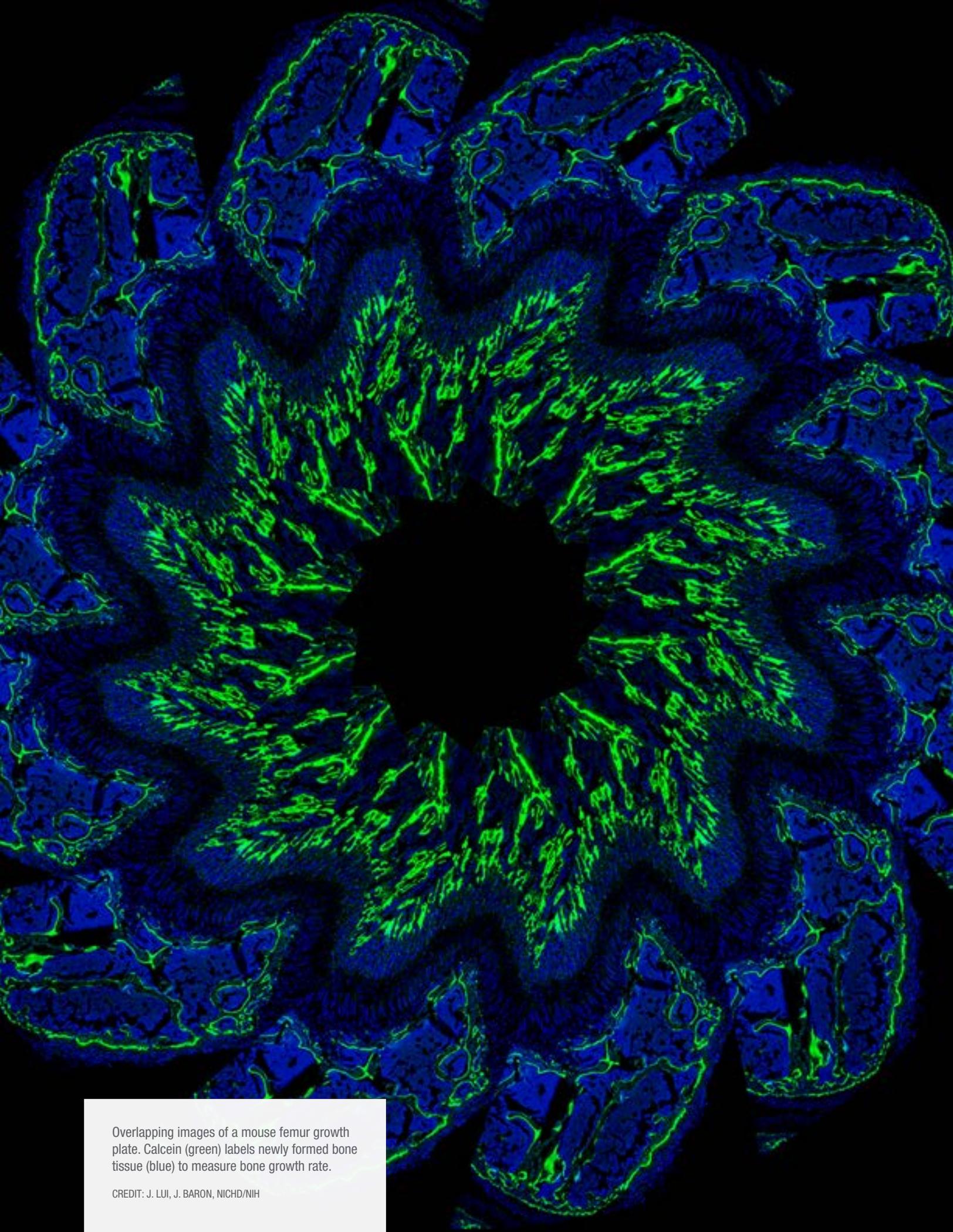
# NICHD

## Strategic Plan 2020

Healthy pregnancies.  
Healthy children.  
Healthy and optimal lives.



Eunice Kennedy Shriver National Institute of Child Health and Human Development



Overlapping images of a mouse femur growth plate. Calcein (green) labels newly formed bone tissue (blue) to measure bone growth rate.

CREDIT: J. LUI, J. BARON, NICHD/NIH

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# Mission

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NICHD leads research and training to understand human development, improve reproductive health, enhance the lives of children and adolescents, and optimize abilities for all.

# Vision

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Healthy pregnancies. Healthy children.  
Healthy and optimal lives.

# Foreword

For more than five decades, NICHD has been a global leader of research involving women, children, and people with disabilities. In the fields of developmental biology, reproductive health, pediatrics, child development, population dynamics, and medical rehabilitation, our commitment to research and training has uncovered new knowledge about health and disease and inspired scientists of all ages to confront the medical issues that affect our world.

Today, the United States and the global community face an array of challenges—such as increasing rates of death related to pregnancy and childbirth—that threaten to erode gains in public health. At the same time, technology breakthroughs, whether in genome sequencing or artificial intelligence, offer new opportunities for scientific discovery and advances in medical practice. NICHD must remain well-positioned to support the research and training needed to address these challenges and opportunities.

In 2018, we began to take a fresh look at our portfolio and chart potential research directions. Institute staff and external stakeholders worked closely together to identify areas in which NICHD can lead, partner and collaborate, and invest in training and infrastructure. Along the way, we reached out to advocacy groups and the general public, who in turn provided input and shared their ideas with us.



The amount of thoughtful feedback we received during this process was remarkable and reflects the significance of our research to the public's health and well-being. We are truly grateful for everyone who helped us bring the NICHD Strategic Plan to fruition.

The strategic planning process has provided us with the opportunity to step back and ask ourselves who we are and where we desire to go. To that end, our plan also includes new NICHD mission and vision statements that crystallize the collective goals and aspirations of our work.

NIH Director Dr. Francis Collins (left), NICHD Director Dr. Diana Bianchi (center), and National Institute of Allergy and Infectious Diseases Director Dr. Anthony Fauci (right) wait to testify before a House Subcommittee on Capitol Hill, April 2019.



Indeed, the strategic planning process has been long, but what appears in this document represents only the beginning. Over the next five years, our scientists and staff will work together to make the plan's research goals and objectives a reality. As our new mission statement says, NICHD will lead research and

training to understand human development, improve reproductive health, enhance the lives of children and adolescents, and optimize abilities for all. Through these efforts, we hope to fulfill our vision of "Healthy pregnancies. Healthy children. Healthy and optimal lives."

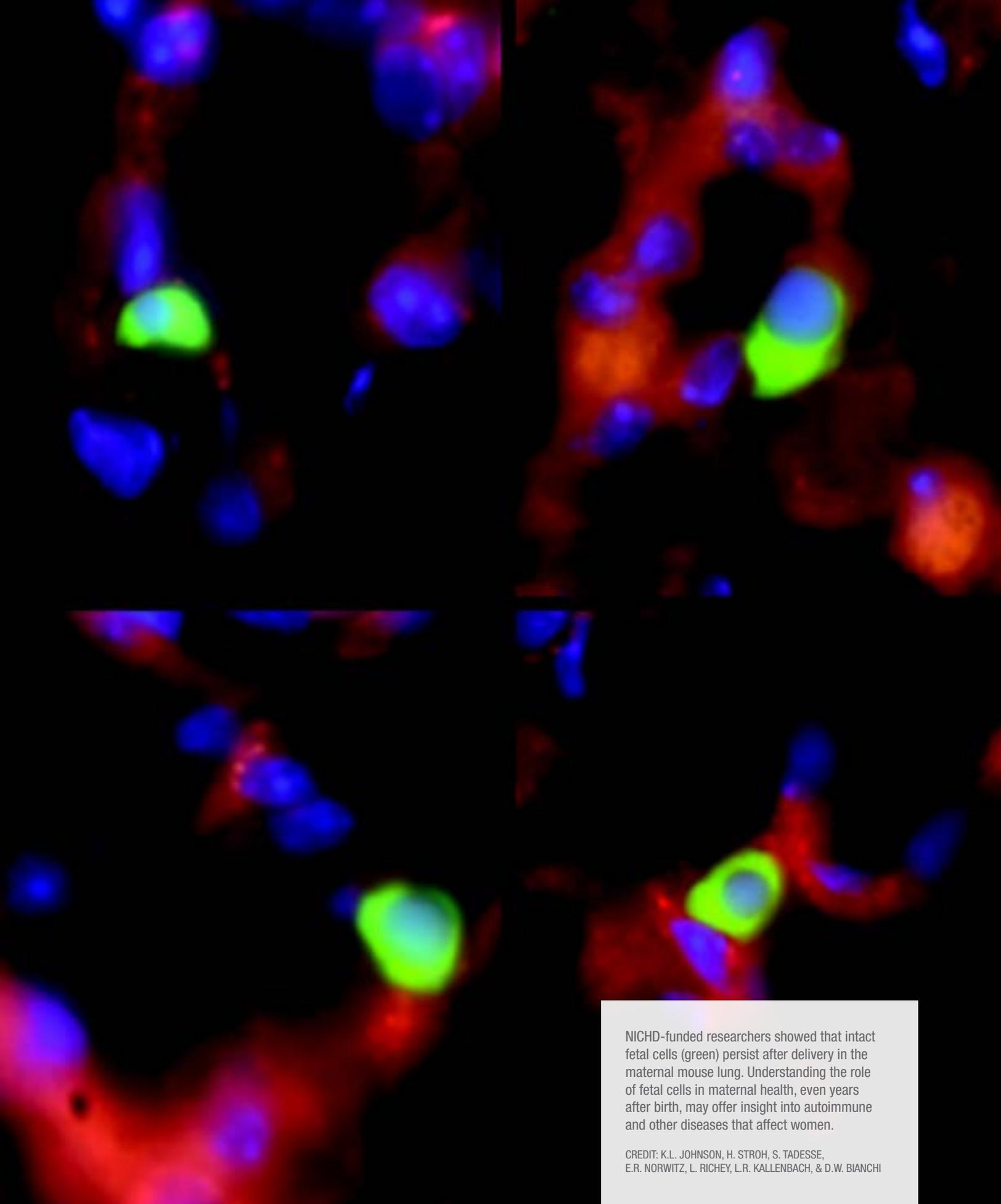
Sincerely yours,

/S/

Diana W. Bianchi, M.D.

Director

*Eunice Kennedy Shriver* National Institute of Child Health and Human Development  
National Institutes of Health



NICHD-funded researchers showed that intact fetal cells (green) persist after delivery in the maternal mouse lung. Understanding the role of fetal cells in maternal health, even years after birth, may offer insight into autoimmune and other diseases that affect women.

CREDIT: K.L. JOHNSON, H. STROH, S. TADESSE, E.R. NORWITZ, L. RICHEY, L.R. KALLENBACH, & D.W. BIANCHI



# Introduction

The *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) is a unique biomedical and behavioral research enterprise that focuses on understanding human development throughout the entire life process, improving the health of women and children, and optimizing the health and function of people with disabilities. The institute was founded in 1962 and is one of the 27 institutes and centers within the National Institutes of Health (NIH).

NICHD's organization includes the Office of the Director, the Division of Extramural Research, the Division of Intramural Research, and the Division of Intramural Population Health Research. The institute also is home to the National Center for Medical Rehabilitation Research, which coordinates research efforts across NIH and the federal government to enhance the health and quality of life of people with physical disabilities.

NICHD recognizes the need to identify priorities that advance its public health mission and ensure proper stewardship of the nation's investment in its research. Since the publication of its last strategic plan, emerging public health challenges, coupled with important advances in NICHD-supported research areas, have changed the scientific landscape and spurred the need for a new path forward.



NICHD research led to the discovery of the gene that causes Rett syndrome. Today, NICHD's work enables diagnosis and effective treatments for kids like Alyssa, shown with her mother, Susan.

CREDIT: SARAH COOK, COOKWIRE PHOTOGRAPHY

This strategic plan was developed to guide the institute's activities over the next five years. It proposes key scientific and public health priorities to advance research, methods to enhance scientific stewardship, and goals to support innovation in management practices and accountability.

This plan establishes ambitious goals to fulfill NICHD's scientific mandate. Given the institute's critical mission and the ongoing advances in science and technology, effective teamwork will be vital to success. Collaborations within NICHD, with NIH colleagues, with federal partners, and with public and private entities will be essential to achieving these goals.

# Scientific Research Themes and Objectives



This electron microscope image provides a close-up view of a 3D woven scaffold on which stem cells are grown. Similarly, cross-cutting topics, such as global health, are relevant to all NICHD research areas. These cross-cutting topics are woven throughout the strategic plan even if they are not explicitly stated.

CREDIT: GUILAK LAB,  
WASHINGTON UNIVERSITY

The NICHD Strategic Plan focuses the institute's research and training efforts to understand human development, improve reproductive health, enhance the lives of children and adolescents, and optimize abilities for all. It presents the institute's research goals and objectives under five broad research themes:

- Understanding the Molecular, Cellular, and Structural Basis of Development
- Promoting Gynecologic, Andrologic, and Reproductive Health
- Setting the Foundation for Healthy Pregnancies and Lifelong Wellness
- Improving Child and Adolescent Health and the Transition to Adulthood
- Advancing Safe and Effective Therapeutics and Devices for Pregnant and Lactating Women, Children, and People with Disabilities

These five themes will enable NICHD to focus its efforts on the most significant public health challenges and advance science in these areas of priority. The institute will measure progress toward these priorities; analyze the scientific, clinical, and public health impact of its research; and periodically report on metrics to stakeholders.

## Cross-Cutting Topics

Several cross-cutting topics emerged during discussions of NICHD's public health and scientific priorities. It became clear that the institute's success in advancing its scientific goals and objectives will depend on its ability to integrate the following topics into each scientific research theme.

### Health Disparities

Pervasive disparities exist in the health of racial/ethnic, rural, low-resource, sexual and gender minority, and other underrepresented populations. Understanding the contribution of social, economic, structural, and regional factors is vital to advancing preventive, diagnostic, and intervention efforts. These factors are particularly important in maternal health and mortality, birth outcomes, infant mortality, child development, and exposure to trauma and injury. Improving approaches in populations that experience specific cultural, social, or access issues will be an emphasis across the research themes.

### Disease Prevention

Disease prevention and health promotion are central to efforts across NICHD. Advancing methods to identify at-risk populations or specific genetic,

nutritional, medical, environmental, social, and behavioral risk factors will enhance the ability to target interventions. The institute will concentrate its efforts on prevention in maternal and infant mortality and morbidity, injuries in children, and risk-taking behaviors in adolescents. Promoting research to prevent adverse health outcomes, improve early detection, and understand the optimal timing of prevention efforts will be critical to success in this area.

### **Infectious Disease**

Infectious agents, such as HIV, continue to pose a significant threat to maternal health and child development. At the same time, pathogens with previously unknown disease-causing properties constantly evolve and emerge. NICHD plans to improve the basic understanding of how infectious pathogens affect pregnant women and young children, address the impact of infections on reproductive and overall health in children and adolescents, and advance safe and effective treatments for pregnant and lactating women, children, and people with disabilities.

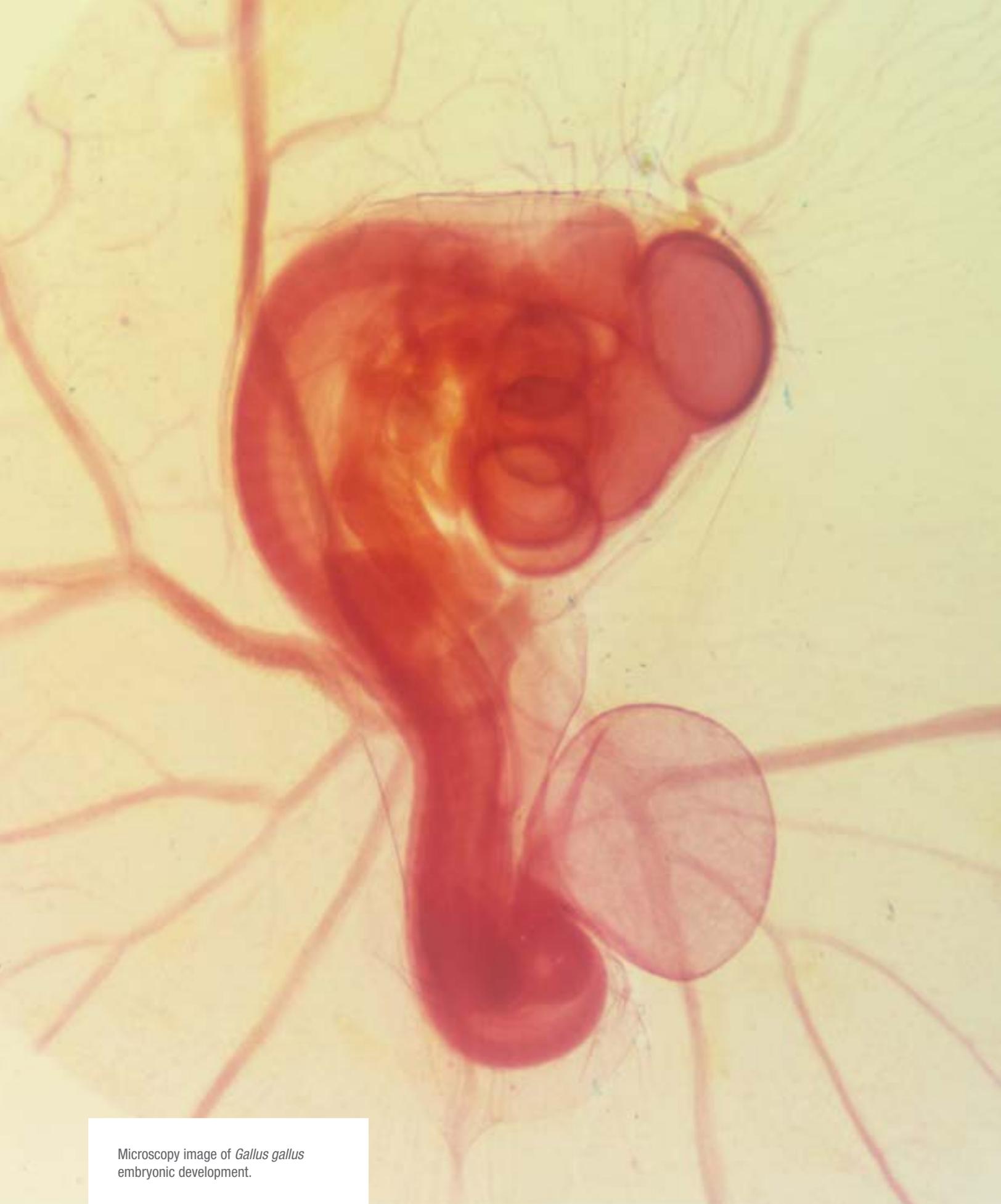
### **Nutrition**

Nutrition is critical to growth and development. New technologies and methods allow scientists to characterize the complex biology of nutrition and the effects of nutritional status on health in a more systems-based approach. The recent revolution in 'omics technologies, including metabolomics, and discoveries related to the interplay

among diet, nutritional status, and the microbiome create important scientific opportunities. These new avenues for scientific discovery will allow NICHD to understand the lifetime impact of nutrition on reproductive health, fertility, pregnancy, and fetal, child, and adolescent growth and development. Of unique interest to the institute is a better understanding of the composition and function of human milk, the effect of maternal nutrition and length of gestation on human milk composition and lactation, and the optimal source of nutrition and mode of nutrient delivery to the infant, especially preterm infants.

### **Global Health**

Disease and disability have no national borders. Because of investments made by NICHD and others, maternal and child survival is improving globally. There is now an opportunity to shift to research aimed at better understanding and addressing long-term health outcomes and chronic conditions of at-risk mothers and children. New interventions to improve pre-pregnancy health will help benefit pregnancy outcomes and prevent prematurity, malnutrition, childhood stunting, disease, and developmental delays. Studying populations globally will also improve domestic capabilities to address disease and risk factors among the culturally diverse U.S. population. Finally, new technologies are emerging to improve assessment and intervention for people worldwide with intellectual, developmental, and physical disabilities, and NICHD will support work in this area.



Microscopy image of *Gallus gallus* embryonic development.

# Theme 1: Understanding the Molecular, Cellular, and Structural Basis of Development

## Goal

Enhance knowledge of genes and gene regulatory networks at the single- and multi-cell levels to understand typical human development and to identify periods of sensitivity in developmental processes that may lead to structural birth defects and neurodevelopmental disorders, including intellectual or developmental disabilities.

## Research Opportunities

Investment in understanding typical developmental processes provides the foundation to investigate underlying mechanisms of congenital conditions, such as structural birth defects, neurodevelopmental disorders, and intellectual and developmental disabilities. Improved knowledge of basic mechanisms of typical and atypical development could reveal key intervention targets to prevent or treat these conditions and improve quality

of life. The earliest processes of human development, in which regulatory molecular networks of genes control development and differentiation of cells, can now be scrutinized with powerful technologies and techniques. Exploiting these tools to map gene regulatory networks, categorize and profile single cell types, and explore genetic variations and epigenetic processes may enable scientists to discern early factors and sensitive periods that raise the risk of congenital anomalies or intellectual and developmental disabilities.



Dr. Brant Weinstein in NICHD's Division of Intramural Research studies early development in zebrafish, mouse, and cavefish models, as well as in cell cultures.



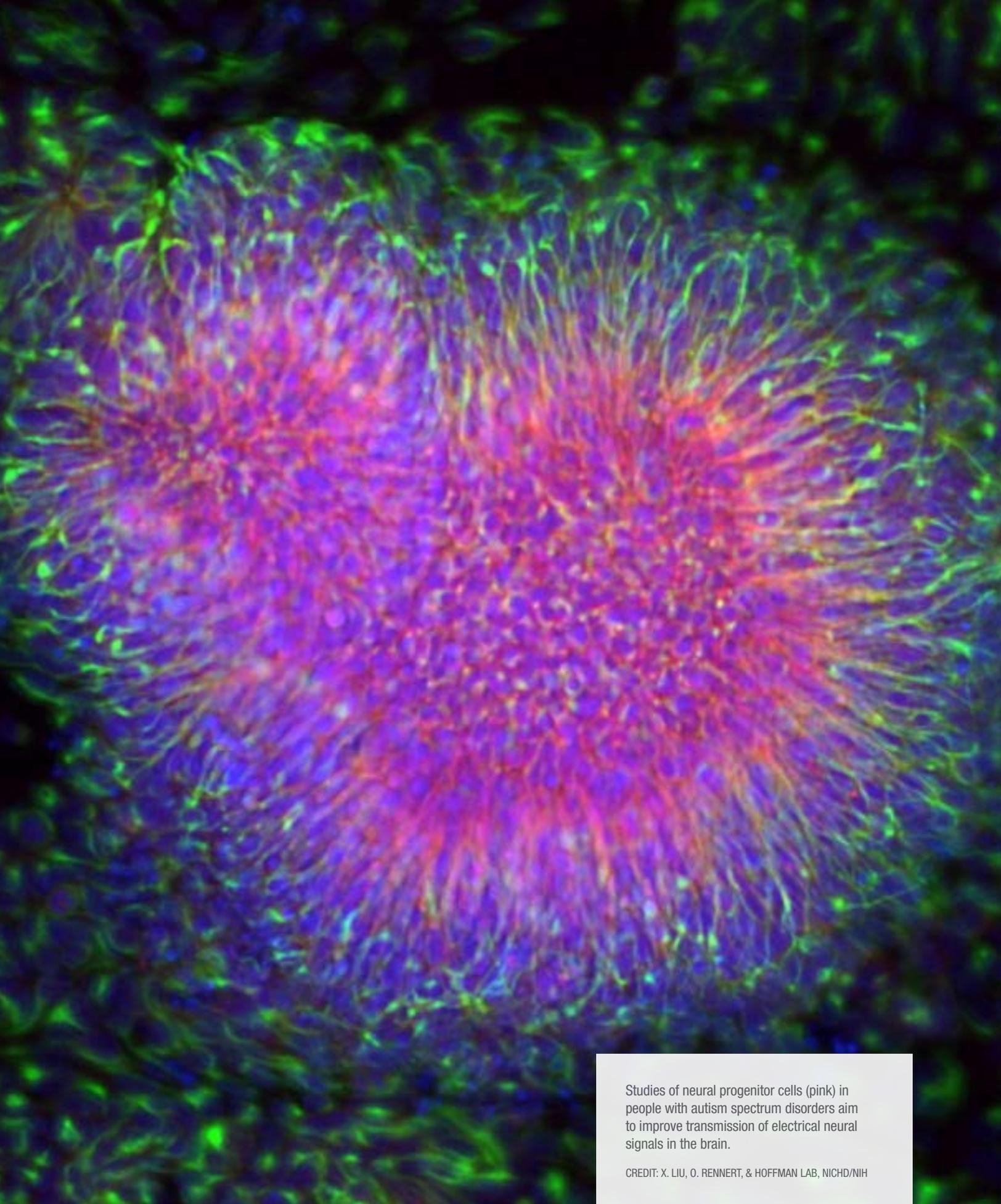
In an NICHD-funded study, an infant with cerebral palsy undergoes constraint-induced movement therapy to improve hand use and control.

CREDIT: N. MAITRE, CHILDREN'S NATIONAL MEDICAL CENTER

New opportunities are emerging to identify how development at the earliest stages may underlie physiologic mechanisms for conditions that may not manifest until years or even decades after birth. Research opportunities in this area include characterizing novel and variant cell types in model organisms and humans, understanding signaling pathways in development, and using genomics and other 'omics methods to examine endogenous developmental processes. Attention to the influence of social and environmental exposures on early development may help to identify potential targets for prevention. This expansion of fundamental knowledge may also allow researchers to harness endogenous developmental pathways and growth factors to create regenerative interventions. Data sharing and advanced analytic techniques, particularly involving genomic datasets, will be key to facilitating rapid advances in these areas of research.

## Scientific Priorities to Advance Public Health

- Reduce the incidence of structural birth defects, neurodevelopmental disorders, and intellectual and developmental disabilities by improving understanding of their origins in the developmental process and identifying potential targets and optimal timing for intervention.
- Characterize the genetic, molecular, and cellular events that determine the initial structure of the cells and pathways that ultimately form the nervous system to better understand early neurodevelopmental trajectories associated with health and disease.
- Use a diverse set of model organisms and other model systems to enhance understanding of typical developmental processes and to identify potential new treatment approaches for people with physical, intellectual, and developmental disabilities.
- Capitalize on new technologies and methods to map global gene regulatory networks that govern development; categorize and profile single cell types as they differentiate and mature, including temporal and spatial characteristics and interactions; and understand the epigenetic processes that regulate cell growth to advance knowledge of determinants of typical and atypical development.



Studies of neural progenitor cells (pink) in people with autism spectrum disorders aim to improve transmission of electrical neural signals in the brain.

CREDIT: X. LIU, O. RENNERT, & HOFFMAN LAB, NICHD/NIH



## Theme 2: Promoting Gynecologic, Andrologic, and Reproductive Health

### Goal

Enable women and men to manage fertility and minimize the impact of gynecologic and andrologic conditions in support of lifelong reproductive health.

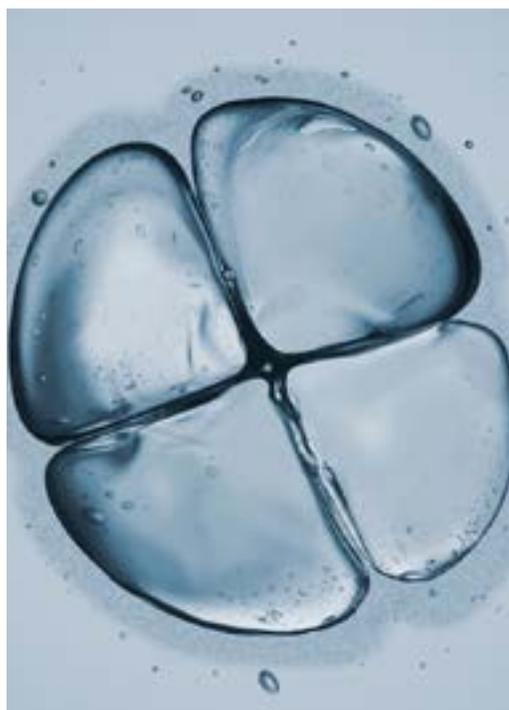
### Research Opportunities

There is an opportunity to improve basic biological understanding of the female and male reproductive organs and to develop knowledge that may lead to treatments for conditions that affect them. NICHD is interested in the use of integrated genetic and phenotypic exposure data to understand the underlying mechanisms of conditions such as endometriosis, fibroids, pelvic pain, vulvodynia, pelvic organ dysfunction, undescended testes, cryptorchidism, varicocele, and other factors that affect gynecologic and andrologic health. Understanding the basic biology of healthy reproductive development, especially the role of menstruation and endometrial biology, could lead to new avenues for addressing gynecologic conditions. Characterizing how gynecologic disorders emerge at the onset of puberty and assessing how the timing of puberty affects reproductive development and gynecologic disorders could lead to new prevention and treatment approaches. The institute will expand basic and translational research efforts, including the study of social and environmental influences, to identify modifiable factors to solve infertility. Expanding the options that allow women and men to manage their fertility will continue to be an area

of focus for NICHD. Scientific efforts to develop biomarkers for reproductive aging and to reduce the impact of andrologic conditions are also required.

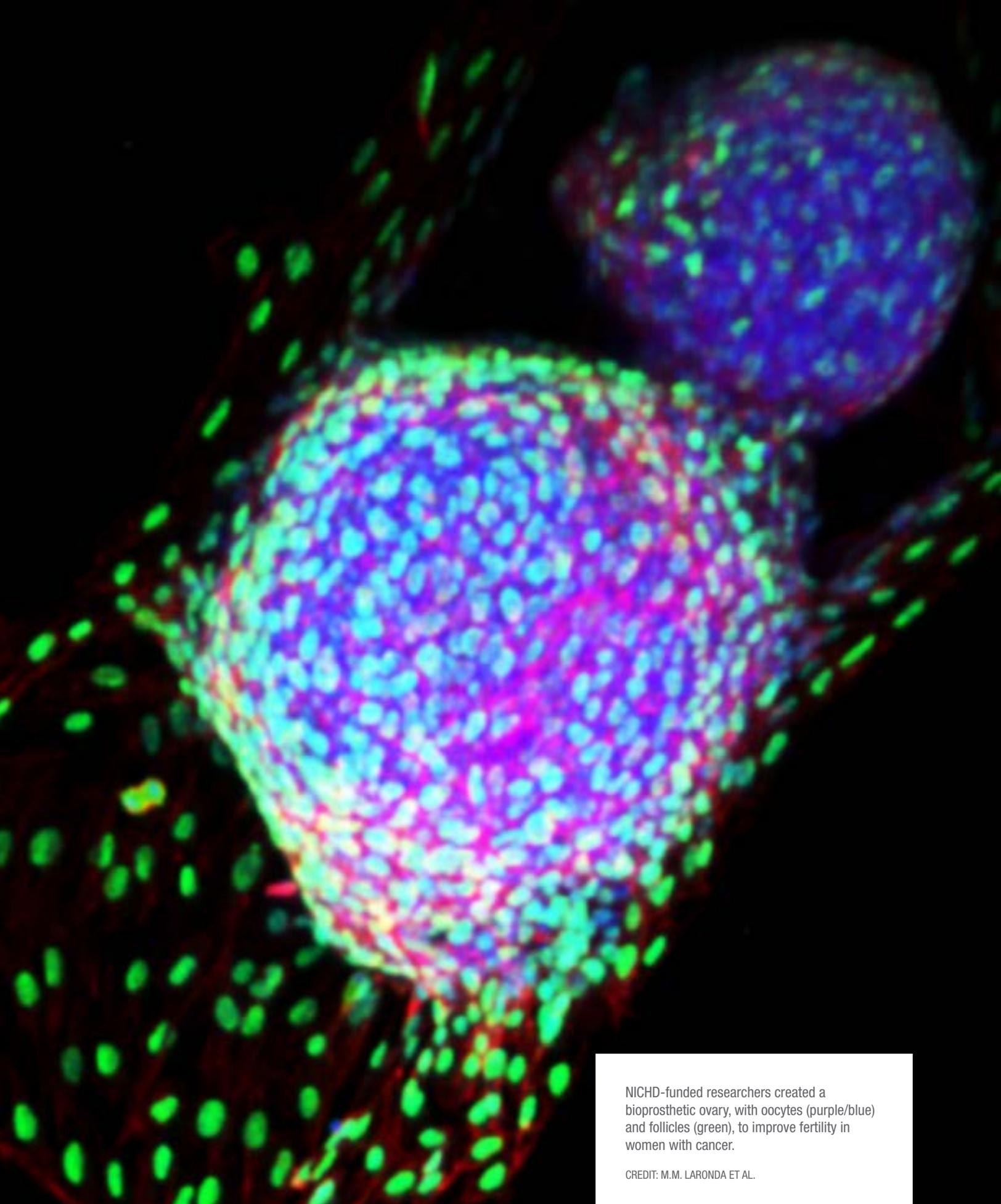
### Scientific Priorities to Advance Public Health

- Understand developmental processes that result in abnormalities in the female and male reproductive tracts. Include an emphasis on factors that contribute to the initiation of puberty and determine the tempo of developmental changes during this time.





- Characterize age-related changes in the reproductive system and their impact on reproductive outcomes, particularly infertility and the health of children born to older parents. Discover factors that contribute to delayed pregnancy, especially social or economic factors, and their association with maternal and child outcomes at the individual and population levels.
- Identify biologic, social, and environmental factors that can lead or contribute to idiopathic female and male infertility and/or early pregnancy loss. Apply this knowledge to expand technologies or methods for fertility stimulation, fertility preservation, and/or contraception. Integrate advanced 'omics and novel model systems to enhance this research.
- Use model systems to uncover factors that lead to gynecologic and andrologic conditions. Expand the genomic understanding, phenotypic characterization, and use of advanced 'omics technologies to inform new prevention and treatment strategies.



NICHD-funded researchers created a bioprosthesis ovary, with oocytes (purple/blue) and follicles (green), to improve fertility in women with cancer.

CREDIT: M.M. LARONDA ET AL.



## Theme 3: Setting the Foundation for Healthy Pregnancies and Lifelong Wellness

### Goal

Improve pregnancy outcomes to maximize the lifelong health of women and their children.

### Research Opportunities

Exploring the developmental origins of health and disease is fundamental to the mission of NICHD. These efforts include the development of early indicators of threats to maternal health during pregnancy, such as preeclampsia, gestational diabetes, postpartum hemorrhage, and thromboembolism, to inform prevention efforts. This work also includes understanding how pregnancy-related conditions contribute to maternal morbidity and mortality, stillbirth, preterm birth, and the long-term health of women and their children. By studying the impact of genotypic, phenotypic, and environmental factors on pregnancy, researchers are now positioned to determine the biological underpinnings of complications and to identify potential targets for intervention. These efforts will incorporate new and/or existing datasets to better understand pre-pregnancy factors, such as obesity, and other conditions. Expanded study of the placenta, including noninvasive methods to determine placental health in real time, will play a key role in this research area. New prevention strategies will be discovered by considering maternal lifestyle factors (e.g., weight, exercise, and diet) and other influences before or



during pregnancy that promote health or lead to disease. Using population health and other strategies, NICHD will strive to understand contributors to maternal morbidity and mortality, pregnancy loss, preterm birth, and neonatal morbidity and mortality. Understanding these factors will help to identify targets for effective prevention strategies and approaches to reducing health disparities. The evaluation of interventions early in pregnancy to protect the health of the woman and her fetus will be a vital component of this research.



## Scientific Priorities to Advance Public Health

- Understand the human gestational clock and the potential causes of preterm birth through basic, translational, and clinical research.
- Improve the survival of infants born preterm or at low birthweight and optimize their outcomes by understanding the roles of early interventions, nutritional factors, the microbiome, and social and environmental support.
- Characterize pre-pregnancy and pregnancy factors that can raise the risk of adverse maternal conditions. Use emerging technologies and big data analytic methods, such as artificial intelligence, to integrate genomic, nutritional, social and behavioral, and exposure data to inform prevention efforts and address health disparities.
- Use basic and translational science approaches to further elucidate the role of the placenta in pregnancy outcomes and in the long-term health of the mother and infant. Continue to develop technologies and methods to monitor the placental function of animal models and humans in real time.
- Develop targeted strategies to improve the prevention of and response to labor and delivery complications that lead to maternal morbidity and mortality. Extend studies of key adverse events to the postpartum period (“the fourth trimester”) to include hemorrhage, mental health conditions, and cardiovascular events, emphasizing populations affected by health disparities.



Knowing how placental villi and vessels develop is key to correcting problems and improving outcomes.

CREDIT: R. ROMERO & PERINATOLOGY RESEARCH BRANCH, NICHD/NIH



# Theme 4: Improving Child and Adolescent Health and the Transition to Adulthood

## Goal

Advance understanding of typical and atypical child development in contemporary cohorts, with an emphasis on identifying sensitive time periods when prevention and treatment strategies will have the greatest impact. Improve the transition from adolescent to adult health care, especially for adolescents with disabilities or chronic health conditions.

## Research Opportunities

NICHD will continue to lead the scientific exploration of typical child development, with an emphasis on specific biological, social, environmental, and other factors that contribute to health and disease. This scientific focus aims to understand the developmental impact of diet and nutrition, the microbiome, physical activity, sleep, adverse childhood events, and early and/or prolonged exposure to technology and digital media. The timing of these exposures and the opportunity to either prevent or mitigate poor outcomes will be a primary focus across childhood and adolescence. Moreover, identifying optimal time periods for intervention after critical illness or traumatic injury or in the context of intellectual, developmental, and physical disability promises to yield new approaches to understanding plasticity and promoting functional adaptation. Throughout this work, there will be a continued focus on social determinants of health and the impact of health disparities on intervention efforts across development. The institute also aims to better understand the developmental changes that occur during puberty and how these changes affect both adolescent health and longer term outcomes.

Finally, NICHD will lead efforts to improve the transition of adolescents to adult healthcare providers, especially for those with chronic conditions or illnesses, disabilities, or childhood exposures that require special consideration, such as exposure to trauma or violence. Improving this transition and exploring methods to improve health literacy, enable self-management, and encourage adherence to existing treatments among adolescents, as well as ways to enhance adult provider



CREDIT: CRIBS FOR KIDS®



knowledge of pediatric conditions, will be accomplished through research efforts at NICHD and in coordination with collaborating institutes that specialize in specific diseases or conditions.

### **Scientific Priorities to Advance Public Health**

- Continue to identify risk-reduction strategies that address infant mortality domestically and globally, as well as efforts to understand the root causes of sudden infant death syndrome and sudden unexpected infant death.
- Determine in typically developing children how exposures to social and environmental factors, such as diet and nutrition, technology and digital media use, sleep habits, physical activity, and infectious agents, affect

neurodevelopment, neuroplasticity, and health outcomes. Include efforts to understand how the timing of these exposures influences development and health using advanced methods in population research.

- Assess and explore prevention and treatment strategies to address the leading causes of trauma and injury in children and adolescents, including violence, maltreatment, accidental injury, self-injurious behavior, and motor vehicle accidents. Develop critical care and rehabilitation pathways to optimize recovery for children who experience critical illness and/or traumatic injury.
- Characterize typical and atypical physical, social, and emotional development in adolescence to enable the identification of sensitive periods for establishing and reinforcing health-related behaviors, optimizing the timing of interventions, and preventing the adverse effects of traumatic exposures on psychosocial outcomes, high-risk behaviors, disease, or disability.
- Improve the transition to adult health care for young adults, especially for those with chronic conditions; those with intellectual, developmental, or physical disabilities; and those who have experienced injury or trauma. Develop measures that may help determine successful transition, at the individual, provider, or system level, to improve care for adolescents.





Look at  
me now!

Despite some risks, prenatal surgery to repair the most severe form of spina bifida offers better results than traditional repair after birth. NICHD pioneered the procedure, which reduces the need for a shunt and increases the chances that kids like Evalyse will walk and run without assistance.

CREDIT: CHILDREN'S HOSPITAL OF PHILADELPHIA

# Theme 5: Advancing Safe and Effective Therapeutics and Devices for Pregnant and Lactating Women, Children, and People with Disabilities

## Goal

Lead efforts to develop, test, and evaluate new and existing therapeutics and devices to find safe and effective solutions that meet the unique needs of pregnant and lactating women, children, and people with intellectual and physical disabilities.

## Research Opportunities

Pregnant and lactating women, children, and people with intellectual and physical disabilities are often prescribed therapeutics that have not been adequately tested for their specific needs. Pharmaceuticals may clear from the body more rapidly in some of these populations, necessitating a higher dose to be effective; or they may accumulate in the blood for longer periods, requiring a lower dose for safety. Pregnant or lactating women who take medications for chronic health conditions do not have enough information to assess whether and at what dose these treatments are appropriate; neither do their healthcare providers. At the same time, leaving a chronic condition untreated could harm the pregnant woman, the fetus, or both. Advances in pharmacogenomics and bioinformatics now make it possible to better understand how factors such as obesity, nutrition, and other exposures affect the action of drugs. Applying these methods to the study of pharmaceuticals in children, pregnant women, and people with disabilities could be beneficial. There are few incentives for industry to conduct such research, particularly for drugs that are off-patent, making the government's role in this research even more critical.

NICHD will continue to lead research efforts to establish the scientific evidence needed for effective treatment of pregnant and lactating women, children, and people with intellectual and physical disabilities. The institute will also lead efforts to assure that assistive and medical devices are effective and optimize function for children (including critically ill children) and people with disabilities. These efforts will benefit from multidisciplinary collaboration with researchers in fields such as



NICHD Deputy Director Dr. Alison Cernich (front, third from left) with the National Advisory Board on Medical Rehabilitation Research, which advises NICHD leadership on ways to coordinate rehabilitation research across NIH and the federal government.



computer science and engineering. New approaches in the design, manufacture, and customization of medical and assistive devices will facilitate these research advances.

### **Scientific Priorities to Advance Public Health**

- Conduct and support foundational research on the development of therapies, including pharmacokinetic, pharmacodynamic, pharmacogenomic, dosing, and formulation studies, to ensure that these treatments meet the needs of pregnant or lactating women, children, and people with disabilities.
- Identify specialized biomarkers, new modeling approaches, and improved outcome measures to support the

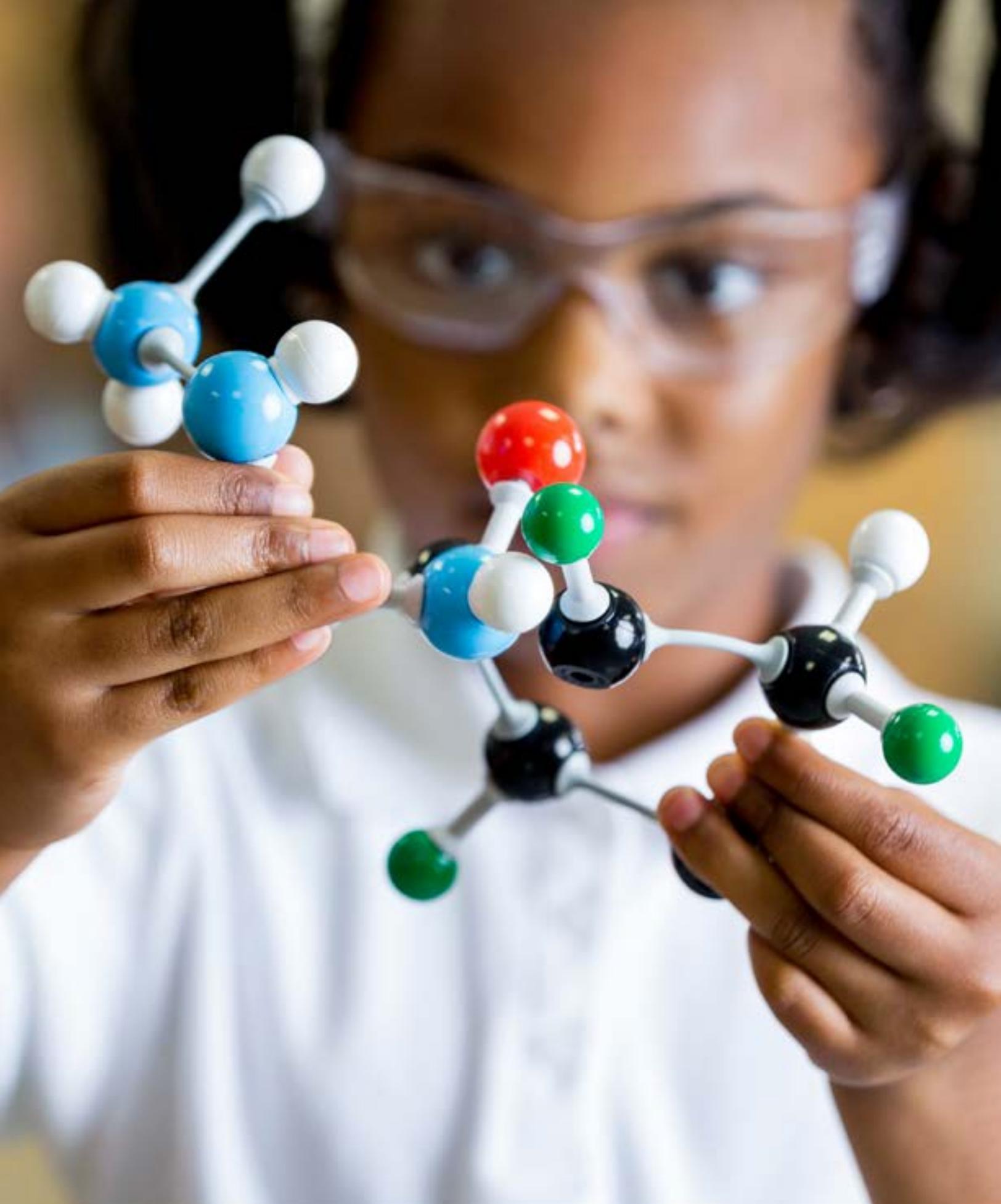
use of pharmacotherapies and reduce barriers to testing these therapies in pregnant and lactating women, children, and people with intellectual and physical disabilities.

- Support clinical research to test and evaluate therapeutics and medical devices used by pregnant and lactating women, children, and people with intellectual and physical disabilities.
- Use large-scale datasets—such as electronic health records, research networks or registries, or other big data approaches—to measure exposure responses to therapy and device use among pregnant and lactating women, children, and people with disabilities.



A child with Down syndrome participates in the University of Delaware's GoBabyGo! program, an NICHD-funded effort that helps children with disabilities move and socialize.

CREDIT: UNIVERSITY OF DELAWARE PHOTO SERVICES



# Aspirational Goals

Setting aspirational goals can spur scientists to consider novel approaches in pursuit of research objectives. The following goals can be considered challenges to the scientific community to harness its shared knowledge to understand human development or improve the understanding, prevention, diagnosis, or treatment of specific diseases or conditions. While the goals in this section are perhaps beyond reach by 2024, NICHD encourages the field to transcend what is currently considered possible to advance research that could lead to healthy and optimal lives for all.

- Identify biomarkers of atypical neurodevelopment that can establish the likelihood of neurodegenerative disorders later in life.
- Accelerate efforts to definitively diagnose, prevent, and treat endometriosis, a disease that affects an estimated 10 percent of women in the United States and results in chronic pain, infertility, and a higher risk of some cancers.
- Identify genomic changes and exposure risks that explain or predict fetal loss, using advanced technological approaches and population-based study methods.
- Use the growing understanding of immune factors in pregnancy and placental development to determine reasons for pregnancy rejection, mechanisms to prolong at-risk pregnancies, and ways to transfer this knowledge to other medical needs, such as organ transplantation.
- Optimize infant survival by synthesizing human milk, capturing all its components and properties, and individualizing it to the characteristics of the infant's mother.
- Enhance the survival and healthy development of preterm infants by exploring the role of environmental factors, such as feeding methods and nutritional support, human touch, and music and lighting.
- Facilitate application of precision medicine approaches in children by capitalizing on advances in genomics and by updating normative data on the growth and development of a diverse population of children, including those with intellectual, developmental, and physical disabilities.
- Discover how technology exposure and media use affect developmental trajectories, health outcomes, and parent-child interactions in early childhood.
- Advance the ability to regenerate human limbs by using emerging technologies to activate the body's own growth pathways and processes.
- Train the next generation of scientists to harness the techniques necessary for future investigation, such as machine learning and artificial intelligence.

# Scientific Stewardship



NICHD Director Dr. Bianchi addresses clinicians, researchers, and fellows in the institute's Perinatal Research Branch in Detroit, Michigan.

NICHD values its role as a partner in the public trust. The institute strives to support the scientific workforce and the development of research resources and infrastructure that help investigators advance fundamental knowledge. Over the next five years, NICHD will continue its commitment to promoting diversity and inclusion, strengthening scientific infrastructure, providing transparency on performance, and ensuring public accountability.

## **Promoting an Inclusive Scientific Workforce That Fosters Research Training**

NICHD remains committed to the development and advancement of early-stage investigators in a broad array of disciplines relevant to the institute's scientific and public health priorities. Training on new methods and technologies will be key to this effort. Through various programs and initiatives, NICHD will continue to cultivate investigators at critical stages of their

research careers; a primary focus will be an inclusive workforce with an emphasis on the recruitment and retention of those who are underrepresented in the biomedical, biobehavioral, and clinical sciences. NICHD's goal to promote a diverse scientific workforce will require the collective efforts of research and training experts across the institute, with a clear emphasis on mentoring and career transitions throughout the training pipeline. NICHD will strengthen its systemic approach to ensure inclusion, diversity, and support of all trainees and awardees through outreach, recruitment, training, and career development.

## **Facilitating Data Sharing and Access to Biospecimens**

Data sharing and access to biospecimens efficiently expands research capacity and maximizes NICHD's investments by promoting hypothesis generation, increasing the potential for secondary analyses, and encouraging reproducibility. NICHD will continue to support the utility and usability of data collected or created with NICHD funding, with a commitment to safeguarding human participants' privacy and confidentiality. In alignment with the overall NIH Strategic Plan, enhancing the research community's access to data and biospecimens is expected and will be a key part of future investments in shared resources.

## **Partnering to Enhance Science**

Partnerships provide the opportunity to enhance existing resources, recruit the expertise and skills needed to benefit science, expand projects, leverage existing infrastructure, and improve recruitment and retention of participants in clinical research. NICHD will augment

and strengthen its science by entering into a range of agreements with several public and private entities, including not-for-profits, professional societies, and foundations. Continued leadership of trans-NIH committees, task forces, and consortia will also allow the institute to advance its strategic mission and priorities through collaboration with other NIH institutes, centers, and offices. In addition, partnerships with other federal agencies will allow NICHD to expand its efforts to provide the evidence base for future policies and programs that benefit its stakeholder communities.

### **Setting Research Priorities**

NICHD will continue to set research priorities by balancing scientific opportunities and public health needs and incorporating the specific populations and areas of science reflected in our mission. This strategic plan will help guide these priorities,

but the institute will remain flexible to respond to new challenges and/or opportunities. For extramural research, NICHD will continue to rely on peer review, programmatic review from experts and public stakeholders on our advisory councils, and the input of our staff to identify and support meritorious projects and programs. NICHD's advisory bodies will continue to inform the institute's priorities, providing input on both intramural and extramural research programs.

### **Aligning Resources to Support Science**

As NICHD implements its strategic plan, there is a need to ensure that its budget can advance strategic objectives while balancing the need to fund science that enhances the breadth of its interests. NICHD will explore a variety of mechanisms and approaches to achieve this goal. As approaches change, NICHD will measure the



NICHD hosts a panel discussion at the Improving Maternal Health Community Engagement Forum, April 2019.

performance of its programs and identify needed adjustments to advance science. Maintaining flexibility of funding for potential responses to public health emergencies or emerging science will be a component of this objective.

### **Improving Clinical Trial Oversight and Management**

NIH is committed to responsible stewardship, accountability, oversight, and transparency of clinical trials supported by the agency. NICHD will continue efforts in its extramural and intramural research programs to ensure appropriate funding mechanisms and infrastructure, relevant inclusion criteria, milestone planning and progress review, ongoing risk management, and public sharing of clinical trials data. NICHD will also assess the need for new or revised policies to strengthen clinical trials, ensure compliance, and safeguard research participants and their data. Efforts to enhance the rigor and reproducibility of clinical trials are a critical step toward this strategic objective.

### **Monitoring and Evaluating Programs**

NICHD regularly reviews and rigorously evaluates its scientific research and training programs to ensure effectiveness and transparent stewardship of research investments. The institute will enhance its ability to evaluate and track the activities of complex scientific research and training programs; pursue new methods to analyze information on stakeholder participation and perspectives; gather

wide-ranging data on the impact of scientific, organizational, and community collaborations; and develop objective assessments of scientific results and public health effects. Program monitoring and evaluation will inform the development, implementation, and reporting of NICHD efforts and accomplishments.

### **Facilitating Transparency and Communication**

NICHD communications activities help convey the goals, results, and health impact of taxpayer-funded research, reinforcing to the public and other audiences the benefits of their continued investment. NICHD will continue to seek new ways to reach its many audiences through an array of vehicles, including interactive live streaming, visual storytelling, media pitching, social media campaigns, podcasts, and other approaches. The institute will also join in NIH-level efforts to streamline Freedom of Information Act processes and improve fulfillment of document requests. NICHD's legislative and public policy efforts include engagement with and outreach to its many stakeholders about the institute's wide range of research activities. The institute will convey the significance and value of the research it conducts and supports so that stakeholders and policy makers understand how NICHD's funds are being used to improve public health, thus allowing new legislation and policy to better reflect and assist in NICHD's efforts.



# Management and Accountability



Dr. Una Grewal (left), Deputy Director of NICHD's Division of Intramural Population Health Research (DIPHR), and Dr. Neil Perkins, a staff scientist in DIPHR's Epidemiology Branch, during a symposium marking DIPHR's 50th anniversary.

CREDIT: S. GILMAN, NICHD/NIH

An accountable organization looks for opportunities to excel, drive decisions through careful analysis, and encourage responsibility and performance. NICHD will enhance its ability to manage for results, develop its workforce, and encourage excellence in performing administrative responsibilities. These goals will help NICHD adapt rapidly to changing needs and requirements.

## Promoting Workforce Development and Balance

To advance science, the NICHD workforce needs resources and training to ensure it has the knowledge, skills, and technologies needed to support its activities. The institute will enhance the development of its workforce through initiatives aimed at growing leadership, supervisory, technical, and scientific skills. At the same time, NICHD will preserve institutional knowledge by developing policies and standards to ensure continuity of operations and programs. Innovative approaches to

encouraging career development, empowering and valuing staff, retaining expertise, and rewarding outstanding performance will be a focus for NICHD over the next five years.

## Ensuring Infrastructure Innovation

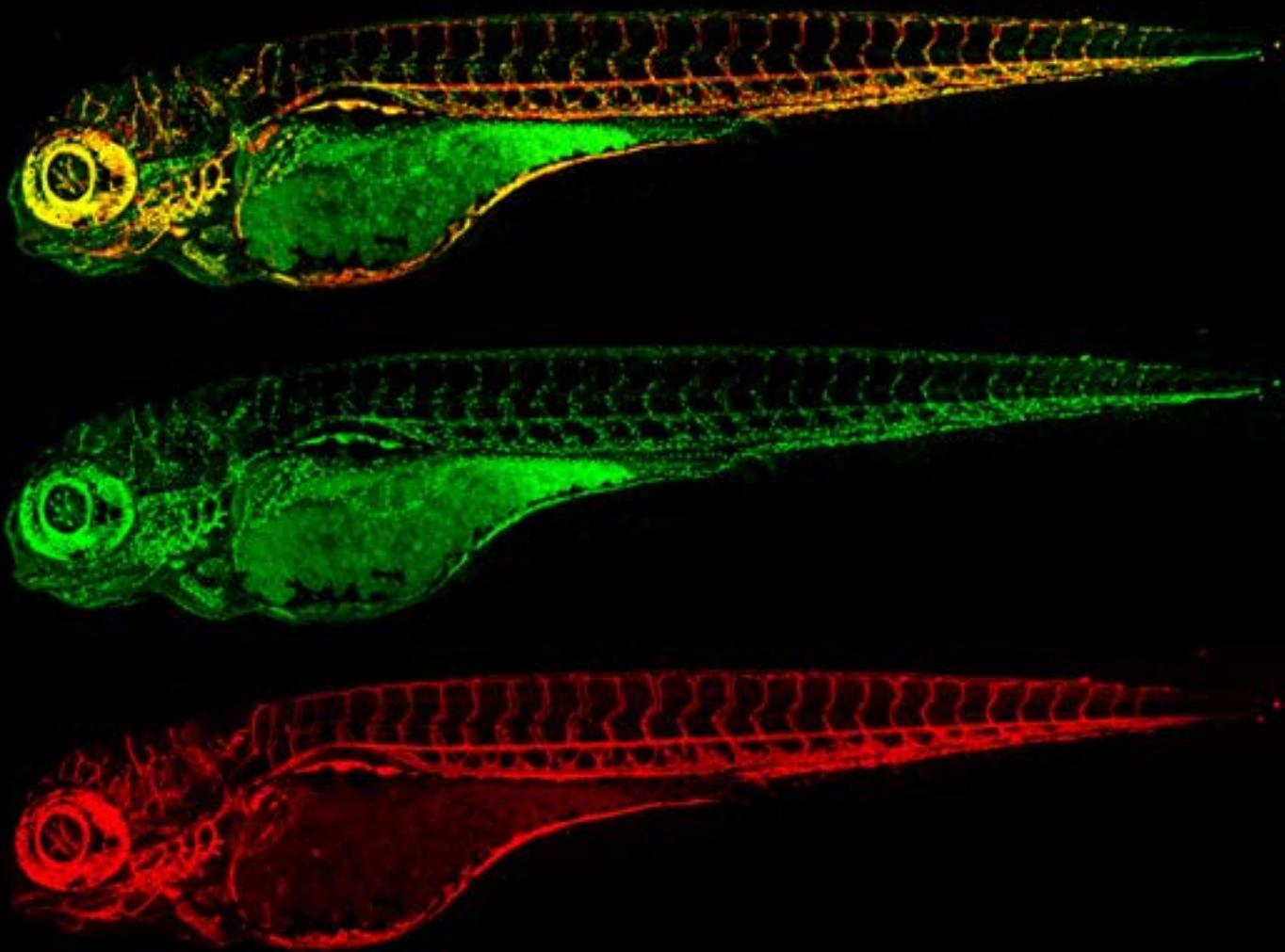
NICHD must ensure that its infrastructure is responsive to the needs of its programs and staff. To accomplish this goal, efforts must focus on effective stewardship of existing resources, anticipation of potential needs of the NICHD workforce, and leveraging ongoing efforts throughout NIH aimed at enhancing common infrastructure.

## Improving Administrative Efficiency

NICHD aims to improve and streamline administrative management and processes while retaining accountability and quality of service. These efforts will transform the institute into a learning organization that anticipates change, adapts rapidly to organizational needs or government mandates, and leverages data to drive decision-making processes.

## Advancing Enterprise Risk Management

NICHD will continue to evolve its risk-management program to ensure appropriate assessment of internal and external risks in an increasingly complex biomedical research environment. Working with NIH leadership, NICHD will continue to evaluate its administrative, operational, and scientific programs and develop standardized procedures to ensure appropriate management. NICHD will also use opportunities to proactively adapt risk-management procedures when confronted with emerging, unanticipated issues.



Transgenic zebrafish with blood vessels (red) and the nuclei of blood vessel cells (green).

CREDIT: D. CASTRANOVA, B. WEINSTEIN, NICHD/NIH

# Appendix I: NICHD Statutory Authority

42 U.S.C. §285g: Purpose of the Institute. The general purpose of the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (hereafter in this subpart referred to as the “Institute”) is the conduct and support of research, training, health information dissemination, and other programs with respect to gynecologic health, maternal health, child health, intellectual disabilities, human growth and development, including prenatal development, population research, and special health problems and requirements of mothers and children.

## Establishment

The early years of President John F. Kennedy’s administration were influenced by senior advisors, notably his sister, Eunice Kennedy Shriver. Mrs. Shriver championed the acceptance of people with intellectual and developmental disabilities (IDDs), while also advocating for research to address the health needs of those with IDDs.

In 1961, Dr. Robert E. Cooke, a pediatrician and another advisor to President Kennedy, chaired a task force on the health and well-being of children. Among the task force’s recommendations was the establishment of a new institute within the National Institutes of Health (NIH). Despite skepticism from some NIH leaders on the need for a separate institute on children, the law establishing the National Institute of Child Health and Human Development (NICHD) was signed on October 17, 1962. NICHD became the first NIH institute to focus on health throughout human life, rather than on a specific disease or organ system. From its inception, NICHD targeted its efforts toward helping the scientific community, policy makers, and public recognize the importance of supporting research not only to help those with IDDs, but also to increase understanding of human development.

## Purpose

Since 1962, NICHD’s statutory “purpose” (see box for current language) has only been amended three times. In 2000, the phrase “gynecologic health” was added. In 2007, the institute’s official name was changed to the “*Eunice Kennedy Shriver* National Institute of Child Health and Human Development” to honor the contributions of Mrs. Shriver. In 2010, another law was passed that updated NICHD’s statutory language to change all references from “mental retardation” to “intellectual disabilities.” In addition, in 1990, Congress established the National Center for Medical Rehabilitation Research within NICHD to support research, training, and dissemination of health information on the rehabilitation of people with physical disabilities. This program was reauthorized in 2016 by the 21st Century Cures Act.



Inaugural National Advisory Child Health and Human Development Council meeting, November 14, 1963.

## Other Statutory Directives

Other provisions of the Public Health Service Act specifically direct NICHD to support certain areas of research in addition to the general mandates governing NIH. Among these provisions, which became law at different points during NICHD's history, are research on sudden infant death syndrome, intellectual disabilities, contraception, and infertility; intramural research on obstetrics and gynecology; child health research centers; studies on both adolescent health and children's health; research centers on Fragile X syndrome; and pediatric research training.

More recently, Congress has provided directives to the Secretary of Health and Human Services (HHS) or to NIH, with the understanding that NICHD would be charged with their implementation. One example, first passed in 2000, is the directive for NIH to create a program of research for conducting pediatric clinical trials with the aim of obtaining pediatric labeling on drugs often prescribed to children (Best Pharmaceuticals for Children Act). Among other provisions of the Newborn Screening Saves Lives Act, NIH is directed to coordinate and expand research on newborn screening (Hunter Kelly Newborn Screening Research Program). A provision of the 21st Century Cures Act directed the HHS Secretary to establish a Task Force on Research Specific to Pregnant Women and Lactating Women to identify the research needed to inform appropriate dosing of medications used by these populations.

# Appendix II: NICHD Organization and Functions

Graduating class  
of NICHD's Division  
of Intramural  
Research Pediatric  
Endocrinology  
Training Program,  
June 2019.

CREDIT: M. VAN DEN NESTE



NICHD is organized into four primary components:

- **Division of Extramural Research (DER)**

DER develops, implements, and coordinates cross-cutting, multidisciplinary research activities within NICHD's mission and supports such research through grants and contracts to colleges, universities, medical schools, hospitals, and small businesses.

- **Division of Intramural Research (DIR)**

DIR conducts laboratory, clinical, and population-based research to seek fundamental knowledge about the nature and behavior of living systems.

- **Division of Intramural Population Health Research (DIPHR)**

DIPHR designs and conducts innovative etiologic and interventional research to promote health and well-being of all populations, including vulnerable subgroups such as pregnant women, infants, and children.

- **National Center for Medical Rehabilitation Research (NCMRR)**

Through basic, translational, and clinical research, NCMRR aims to foster development of scientific knowledge to enhance the health, productivity, independence, and quality of life of people with physical disabilities.

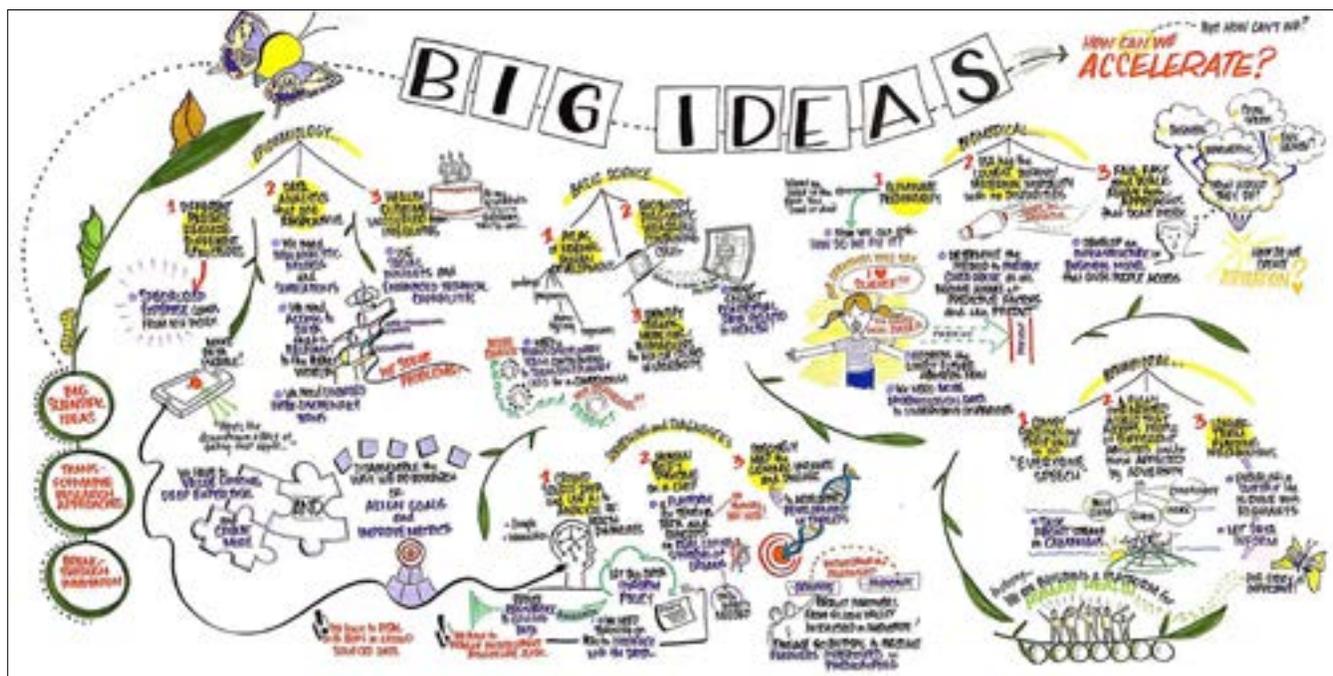
The NICHD Office of the Director (OD) works with these four components and provides overall leadership, planning, direction, coordination, and evaluation of the institute's research programs and activities. OD also develops and monitors internal policies and procedures to effectively and efficiently advance NICHD's mission. For a full organizational chart, visit <http://bit.ly/NICHDOrgChart>.

## NICHD Functions

The key functions of the institute are as follows:

- Provide leadership and formulate research goals and long-term plans to accomplish the mission of improving maternal, fetal, and child health; addressing problems of human development, with special focus on intellectual and developmental disabilities; analyzing family structure and the dynamics of human populations; studying the reproductive processes; and enhancing recovery and quality of life through medical rehabilitation.
- Conduct, foster, and support biomedical and behavioral research through grants, contracts, and studies performed in NICHD laboratories.
- Support training in fundamental sciences and clinical disciplines through individual and institutional research training awards.
- Promote the application of research findings to clinical practice.
- Cooperate in government-wide efforts to improve health and provide consultation to federal agencies and non-federal groups on the development of programs to improve health.
- Coordinate and integrate research efforts with service-oriented health agencies.
- Disseminate information related to research findings to the scientific community, clinical practitioners, policy makers, and the general public.

# Appendix III: Strategic Planning Process



Graphic recording of Big Ideas from the NICHD Strategic Planning Meeting, October 2018.

Science is evolving rapidly, driving the need for NICHD to update its strategic plan. In January 2018, the institute embarked on a process to accomplish this goal that was transparent, focused on science, guided by evidence, and informed by NICHD’s stakeholders. The overarching goal of the process was to identify scientific priority areas in which NICHD can lead, ultimately providing a strategy for NICHD-supported research to improve the health of its primary populations: children, women, and people with disabilities.

The strategic planning process entailed five phases: (1) pre-planning; (2) review of programs, data, and analyses; (3) input from internal and external stakeholders; (4) data review and refinement; and (5) finalizing and publishing the plan. The following are key activities undertaken during these five phases.

## Pre-Planning

NICHD established an internal Strategic Planning Committee to coordinate and manage the process. In addition, a Strategic Planning Working Group (Working Group), comprising 27 NICHD staff members and 53 external participants, was created to inform the early phase of the strategic planning effort. The external members of the Working Group were chosen to represent the range of NICHD’s research portfolio, including scientists and laypeople with multidisciplinary expertise; a third of the group were young investigators. This group contributed ideas on NICHD’s scientific focus areas and on potential research priorities, training and partnership opportunities, and support of emerging technologies.

To facilitate transparency, NICHD established a public-facing strategic plan website (<http://bit.ly/NICHDStrategicPlan>). The site provides a platform to inform the public about the purpose and rationale for a new strategic plan and to provide progress updates. The site offered several ways for the public to actively participate in the process, including a mailbox ([NICHDStrategicPlan@nih.gov](mailto:NICHDStrategicPlan@nih.gov)) to receive and respond to public questions and comments and a social media hashtag (#NICHDStrategicPlan) to initiate categorized online conversations on the planning process via Facebook, Twitter, Instagram, and other sites.

## Review of Programs, Data, and Analyses

NICHD reviewed the following programs, data, and analyses to help inform the strategic planning process: (1) NICHD's statutory authority and legislative requirements; (2) the NICHD Vision and Visioning Process from 2010; (3) the NICHD Division of Intramural Research Strategic Plan; (4) the NICHD Division of Intramural Population Health Research Strategic Plan; (5) an analysis of the current NICHD portfolio; (6) a review of the NICHD budget and financial obligations; (7) an analysis of the impact of NICHD-funded research programs; (8) an analysis of the impact of publications resulting from R01 projects funded by NICHD; (9) an analysis of the success of NICHD research project grants in specific study sections; (10) the NIH Research Plan on Rehabilitation; and (11) a review of the impact of partnerships in which the institute participates.

## Input from Internal and External Stakeholders

In fall 2018, the results from these analyses were presented to the National Advisory Child Health and Human Development (NACHHD) Council (one of the institute's federal advisory committees), the Working Group, the Friends of NICHD (a coalition of not-for-profit organizations and professional societies), and the general public. These data helped set the stage for substantive and informed discussions with NICHD's stakeholders about the scope and impact of the institute's research portfolio.

## Data Review and Refinement

Based on the input and analyses from the earlier phases of the process, an initial set of scientific research themes was assembled for review and refinement by NICHD intramural and extramural staff members. An internal Planning Committee reviewed the proposed themes from the intramural and extramural teams and compiled a draft set of six research themes. These themes were then incorporated into a Request for Information (RFI) that was published in the NIH Guide in January 2019 to solicit public input. The RFI received a robust public response, with 924 total replies. A summary of RFI responses is available at <http://bit.ly/SummaryOfRFIResponses>.

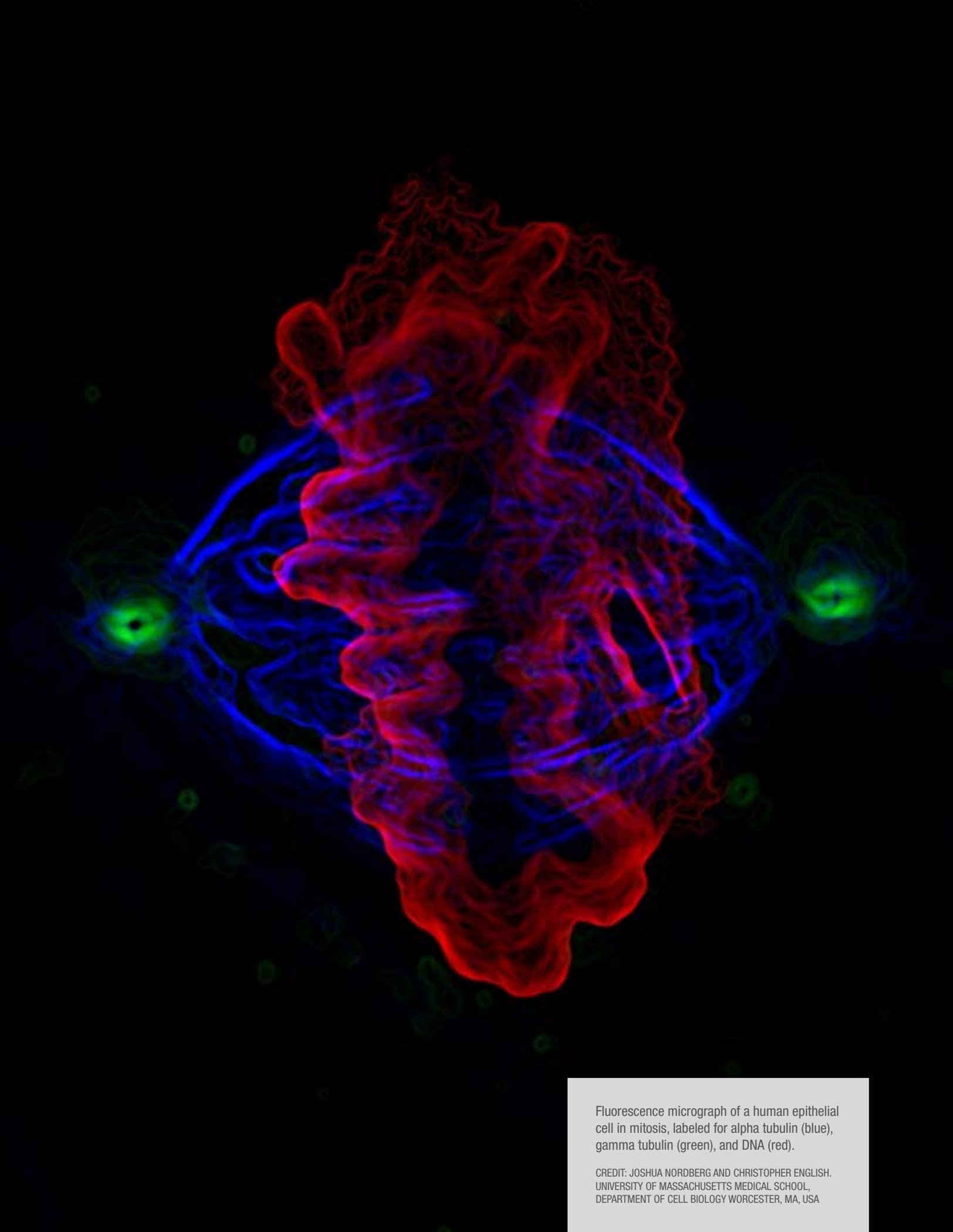
The draft research themes from the RFI were also presented to the NACHHD Council for feedback in winter 2019. The Planning Committee reviewed all suggestions and recommendations from the RFI and Council and then further revised the research themes, narrowing them from six to five.

## **Finalizing the Plan**

The last phase of the process involved deliberations among NICHD leadership on the public health priorities that the institute will address over the next five years. Consideration of these public health priorities informed further refinement of the specific objectives to advance the research themes. NICHD leadership and staff also met to articulate how the institute will continue to enhance scientific stewardship, as well as how to improve management and accountability practices to ensure efficient use of taxpayer resources. These discussions included measures to assess progress of the new strategic plan.

## **Future Progress**

The institute considers the strategic plan to be part of an ongoing discussion with its many research communities and stakeholders. Over the next five years, NICHD will provide regular updates on its progress on these research priorities and on efforts to improve scientific stewardship, management, and accountability of resources, recognizing that a public health crisis or changes in the scientific landscape may necessitate adjustment of these priorities and goals.



Fluorescence micrograph of a human epithelial cell in mitosis, labeled for alpha tubulin (blue), gamma tubulin (green), and DNA (red).

CREDIT: JOSHUA NORDBERG AND CHRISTOPHER ENGLISH.  
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*Eunice Kennedy Shriver* National Institute  
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