

2011 ANNUAL REPORT

WABRORG

Northwest Association for Biomedical Research

Promoting the Understanding of Biomedical Research and its Ethical Conduct



From The Director



NWABR strengthens public trust in research. These words capture who we are as a community. They were chosen by our Board leadership to define, mobilize and inspire every research organization and individual who is a member of NWABR.

How does NWABR join forces with our members to carry out this mandate? Read on...

NWABR strengthens public trust in research...through education and dialogue.

This year, we present the impact of our work through the rich kaleidoscope of dialogue. Dialogue has many translations...from Webster's Dictionary — "a conversation by two or more persons," to C. Otto Scharmer's Four Fields of Conversation — "speaking from seeing myself as part of the whole" (reflective inquiry).

As you peruse the pages that follow, we invite you to take note of the dynamic ways in which you engage with us in dialogue across our northwest region...

- Speaking
- Blogging
- Mentoring
- · Writing and responding to articles and opinion pieces
- Hosting on-site visits with passionate, articulate scientists
- Judging at our high school Student Bio Expo
- Serving on our Task Forces to insure trustworthy research practices
- Providing "safe places" that preempt and prepare for crisis communications
- Participating in our new monthly "Bioethics Salons"—Community Conversations

In historian Jonathan Moreno's recent book — The Body Politic: The Battle over Science in America, he demonstrates how the intersection of society and science has shaped modernday biopolitics, highlighting embryonic stem cell research and synthetic biology as potent examples. Moreno makes the argument that scientists today are suspect. The public believes we talk funny and work in secret silos. "It is all about mutual identification", he stated in a private session in Seattle this fall. "It's not about the issue. It is about the people with whom one identifies." Moreno makes a compelling case; scientists are not people with whom the public can readily identify.

NWABR's 2011 Annual Report is replete with example upon example of how we are changing that perception through the power of dialogue. Thank you for your ongoing support in partnering with us in this essential work. As always, we hope our report sparks additional ideas for continuing the dialogue and strengthening public support for research. Sum aller

SUSAN ADLER Executive Director 44 Society determines how much of our resources will be devoted to finding cures for the diseases that afflict us. That decision needs to be made with as much knowledge as possible. By promoting dialog between biomedical researchers and the public, NWABR plays a crucial role in informing the public of the rewards that ensue from their support of biomedical research. 77

Bob Speth, Emeritus Board member

Professor of Pharmaceutical Sciences College of Pharmacy Nova Southeastern University

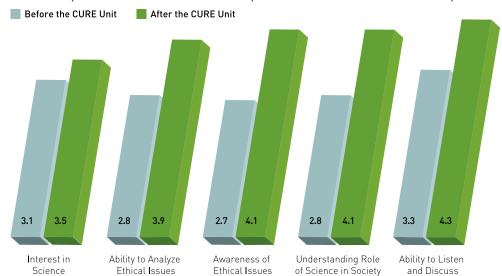
Creating a Classroom Atmosphere of Respectful Dialogue

Animal research. End of life decisions. Stem cell research.

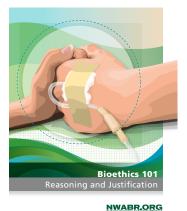
Few topics elicit such strong reactions as these, and many teachers are hesitant to bring controversial subjects into the classroom. NWABR's Ethics in the Science Classroom curricula support students in coming to well-reasoned, fact-driven positions about issues such as these. This is no easy task: justifying such a position involves complex cognitive skills that are challenging to both teach and assess.

NWABR is making a difference. Our latest curriculum, The Science and Ethics of Animal Research, is making a national impact and was recently mentioned in *The Scientist* as an exemplary resource for teaching this important topic. 2011 also marked the completion of NWABR's research study investigating the effectiveness of our teacher professional development and our bioethics resources in promoting student critical thinking, reasoning, and analysis skills. Students who have experienced our curriculum show an increased ability to analyze socio-scientific issues and make well-justified decisions, awareness of ethical issues, understanding of the connection between science and society, and the ability to list and discuss viewpoints different from their own. Our findings are currently being prepared for publication.

Students' Perspectives Before and After Participation in NWABR Ethics Unit (self-reported scores)



In support and recognition of this vital work, in October NWABR was awarded a \$134,000 supplement to our Science Education Partnership Award grant from the National Institutes of Health to offer additional educational resources and programs related to the topic of animals in research. 56 secondary science educators participated in a 3-part special seminar series that included tours of animal facilities in member research institutions, a special workshop led by Primate Center Directors at the Nonhuman Primate Models for AIDS Conference and in-depth professional development in NWABR's recently released curriculum, The Science and Ethics of Animal Research.











NWABR.ORG

research from a very emotional perspective. NWABR's curriculum helps them explore the many issues surrounding animal use and step away from the emotions to make a reasoned logical evaluation of the realities of animals in research. 77 Elise Cooksley, science

Students approach

the idea of animals in

teacher and member of NWABR's curriculum development team

Serving & Strengthening our Research Community

Building Trust for Research with Human Volunteers

In July 2011 the federal Office for Human Research Protections (OHRP) released a notice seeking the opinions of everyone with a stake in the advancement of medical knowledge and the protection of the volunteers who serve as subjects in medical studies. These changes, the most extensive proposed to the regulations governing research with human volunteers since 1979, represent a critical opportunity to strengthen dialogue and build trust between our northwest research community and the public.

NWABR, together with our member institutions from academia, industry and the voluntary health associations, assessed the institutional impacts of the proposed changes and respond directly to OHRP's request for comments. In partnership with the Institute of Translational Health Sciences, a consortium which includes the University of Washington, Fred Hutchinson Cancer Research Center, Benaroya Research Institute at Virginia Mason, Seattle Children's Hospital, and Group Health Research Institute, NWABR co-hosted three town-hall style meetings. NWABR also organized several discussions with the NWABR Board of Directors and individual member institutions.

Experts from several of NWABR's member institutions across the region addressed elements of the changes likely to have the greatest impact on the research community. Wylie Burke, MD, PhD, Professor and Chair, Department of Bioethics and Humanities at the University of Washington led a discussion on the impacts of proposed changes to research involving specimen repositories. Research involving minimal risk to volunteers was the topic of a discussion moderated by Douglas S. Diekema, MD, MPH. Professor, Division of Bioethics, Department of Pediatrics at the Seattle Children's Hospital. Data security management and multi-center, single site IRB review were discussed by Ann Melvin, MD, MPH, Associate Professor, Pediatric Infectious Disease, Seattle Children's Hospital, Suzanne McCoy, MPA, Assistant Director of the Medicine Privacy & Identity Theft Program at the University of Washington, John Soltys, ITS Security Analyst at the University of Washington School of Medicine, and Karen Hansen, Director of Institutional Review Office at the Fred Hutchinson Cancer Research Center.

NWABR's formal response to OHRP was posted along with comments from major research institutions across the country. Ultimately, opportunities such as these for education and dialogue, created by NWABR in collaboration with our partners, empowers our northwest research community to address the complexities and ethical dimensions inherent to research with human volunteers, sets a high standard for the ethical conduct of research, and engenders trust with the public.



Description goes here

NWABR's Recognition



Genetic Alliance, Kelly



Genetic Alliance. Jeanne



Miller-McCune Article



The Scientist Article

These are difficult conversations, as the cultures of law enforcement and an open-access academic institution are very different - but we need to have these conversations. 77

> Jeff Cheek, Associate Vice Provost for Research Compliance and Operations, University of Washington

Partnerships With Law Enforcement Agencies

Cultivating a climate in which ethical research practices flourish requires transparency, the timely sharing of research discoveries through publication, and unfettered communication between scientists. Yet in the final days of 2011 the country read about ethical issues facing scientists and security experts about sequestering data that could be used for nefarious purposes. NWABR's mission of strengthening public trust for biomedical research and our work to support the ethical conduct of research positions us at the hub of this issue.

Through our partnership with the Federal Bureau of Investigation (FBI)'s Weapons of Mass Destruction Directorate, NWABR convened a diverse group of stakeholders and research leaders throughout the northwest to engage three separate scenario-based workshops hosted at University of Idaho, University of Washington and Seattle BioMed. The focus of this particular dialogue was on dual use research – important, legitimate studies that yield technologies or information that can be misused to threaten public health or safety. Leadership teams from NWABR member institutions included professionals from emergency response, environmental health & safety, compliance, government and public communications, facilities management, legal affairs and administration.

Together, nearly 200 attendees representing over 50 organizations clarified roles and responsibilities, identified benefits and potential obstacles to improving cooperation, and increased awareness about effective communication methods between security and research organizations. By providing a safe place for these sensitive discussions and leveraging our deep resources and diverse relationships, NWABR is working collaboratively with our members and partners to strike an appropriate balance between biosecurity and scientific disclosure.

In the Community

Life Sciences Research Weekend, Nov. 4-6, 2011

Face-to-face dialogues with scientists and innovative hands-on science activities provided memorable experiences for over 5600 children and adults that attended Life Sciences Research Weekend in November. NWABR partnered with Pacific Science Center to present the 5th annual, 3-day event that celebrated the innovative life sciences research in our state. More than 280 researchers and volunteers representing 23 organizations from around the state took part in the event, bringing their science to life and becoming role models for our next generation of scientists.







I feel that I really grew in my knowledge and understanding of the issue and made valuable connections.

> Community Conversation **Participant**

Community Conversations

Our new public discussion series designed to strengthen public trust through education and dialogue. Fueled by excellent refreshments and navigated by a facilitator, we discover together the nuances of issues that pervade biomedical research while reflecting on ethics and personal perspectives. Feedback from our 53 attendees demonstrates strong engagement and intent to more deeply contribute to the research process. (continued on next page)







A monthly series that will continue into 2012, our first three events were facilitated by Kelly Edwards, PhD, UW Bioethics and Humanities; Lara Mangravite, PhD Sage Bionetworks; and NWABR's Jennifer Wroblewski, MPH in partnership with Heather Kirkwood, VP and Director of Outreach for the Hermansky-Pudlak Syndrome Network. Topics encouraged thoughtful dialogue about duty to participate in medical research, how to accelerate research while protecting study participants and special issues within rare disease research illustrated by film excerpts from RARE, co-directed by Maren Grainger-Monsen, MD and Nicole Newnham. NWABR is proud to honor our Community Conversation presenting partners: 415 Westlake, Kakáo Chocolate and Coffee, Union and the Institute of Translational Health Sciences.

I've never before thought about the mental health struggles people with rare disease might have, or how people might feel being in a clinical trial.

Community Conversation Participant

Linking Science Volunteers and the Community

Increasing the dialogue between scientists and the public is an important step in breaking down negative stereotypes and planting the seeds of interest in science careers. NWABR serves as a hub connecting researchers with volunteer opportunities in the community. We initiated an online sign-up for volunteers and maintain a current list of community volunteer opportunities (http://nwabr.org/community/volunteer-opportunities). NWABR staff and volunteers from our member organizations hosted activity tables at multiple family science events and judged at science fairs and student presentations.

Blog Growth

In our first year of blogging, we published more than 75 posts, viewed by over 10,000 readers on our main blog, "Thank Research!" Our most popular posts included coverage of our 2011 Youth Ethics Summit at the Institute for Stem Cell and Regenerative Medicine at the University of Washington. Students enjoyed "Stem Cells 101Đ by Professor Tony Blau, MD and Director of the Institute, extensive tours, and participating in discussions about bioethics. Another popular post covered a lecture entitled "Henrietta Lacks: Ethics at the Intersection of Health Care and Biomedical Science," given by Dr. Ruth Faden, PhD, MPH, of the Johns Hopkins Berman Institute of Bioethics. Dr. Faden illuminated ethical concerns from the story of Henrietta Lacks that are still relevant today in patient consent, biorepositories, and participation in research. We have revisited these issues through many other programs, such as NWABR's Community Conversations series.

Inspiring Students and Teachers

Expo

While science fairs are not typically thought of as a forum for international communication, the 2011 Student Bio Expo piloted a program which focused on generating conversation between students in Seattle and Kenya. Using technology like Skype and Google Docs as a means to connect, Seattle students were inspired by the Kenyan teens, who see first-hand the ravages of HIV, malaria, and tuberculosis,

This experience has opened my eyes to how important education is. In my global health team, our partners in Kenya provided us with so much more than we expected, reminding me that everyone's voice is truly important. Through this project I became more aware of global diseases and the importance of being a global citizen.

Roosevelt Student



MWABR has created something special and I am excited to be a part of it again.

Brianna Armour

2006 Expo Participant, 2012 Expo mentor

the "unholy trinity of infectious disease." One Roosevelt High School student commented that she "felt empowered by [her] partners in Kenya, who were so fun and helpful." The SeaVuria program, named for the places where the students lived--Seattle and the village of Vuria, fostered projects that not only focused on the biological aspects of infectious disease, but also emphasized the importance of implementing social programs as a means to help communities in Kenya. By cultivating relationships with students on the other side of the world, Expo students learned that there's a human side to science.

Over 300 students presented projects at the 11th Student Bio Expo in 2011. Two hundred students took advantage of the opportunity to be mentored by 135 professionals in scientific or medical fields. In addition to the SeaVuria projects, these year-long mentorships contributed to award-winning and crowdpleasing projects such as a teaching lesson which used pasta to demonstrate natural selection and a soap opera dramatizing the diagnosis of type-1 diabetes to a teenager.

L Expo made me look at science in a whole new way; it was amazing to see all the projects that people come up with and how there are so many different ways that things can be connected to science.

Eastlake Student

Out-of-School ("Informal") Science Education Partnerships

Science is everywhere and showcasing its relevance in after-school programs has a lasting impact. NWABR staff presented hands-on workshops focused on the science behind lotions to middle and high school students associated with Girls Scouts, the Association for Women In Science GEMS program, Expanding Your Horizons and community after-school science programs. Over 250 students and adults made lotions and gained an appreciation for the importance of reading labels, safety testing of ingredients and the science of emulsions.

NWABR Becomes Partner on Collaborative Digital Library

With funding from the NSF, NWABR joined the Archive of Teaching Resources (www.apsarchive.org), a Collaborative National Science Digital Library sponsored by the American Physiological Society. The Archive provides increased national exposure for our educational materials, with peer-reviewed resources for K-12, undergraduate, graduate, professional, and continuing education. Within the NWABR community, introducing the Archive at teacher professional development events offers the opportunity to engage educators in building curricular sets, rating items in the Archive, and conversation regarding preferred resources and best practices.

Each resource in the Archive has been reviewed for scientific accuracy and appropriate use of humans or animals in teaching. Archive Partners have catalogued more than 4,000 free resources covering a variety of topics, especially physiology, anatomy, embryology, human biology, invertebrate biology, neuroscience, and career exploration and development. Other partners include Society for Developmental Biology, Human Anatomy and Physiology Society, American Association of Anatomists, and the Massachusetts Society for Medical Research. With over 9000 unique users/month, the Archive is a popular and growing source for accurate educational materials. By including NWABR's materials in this highly selective peerreviewed Digital Library, we can be a catalyst that deepens the dialogue about research in classrooms across this country.







Student Research Fellows

Seeing is believing! High school students' dreams about a possible career in science were reinforced after dialogue and lab tours with scientists and staff members at nine NWABR-member sites. The two week program, funded through NWABR's NIH NCRR SEPA grant, Collaborations to Understand Research and Ethics (CURE), enabled 26 high school students to learn about the ethical decisions in the process of biomedical research both in the Seattle area and in Eastern Washington.

The CURE grant also enabled fifteen high school teachers to visit to fifteen research institutions during their summer program with NWABR. The ensuing discussions with scientists provide insights that can be passed on to their students.

NSTA SEPA Booth

NWABR serves as a leader in science education regionally and nationally: At the 2011 National Science Teachers Association meeting in Seattle, we served on the local organizing committee, presented 5 sessions on our cutting-edge science resources to over 250 teachers, and spearheaded a booth featuring NIH Science Education Partnership Award programs from across the West Coast.

I used to think animal research was something out of a horror film, the torture of poor and defenseless creatures.

Now I understand it to be completely humane, and necessary for the advances we have today.

Kelsey Condon, 11th grade, Student Research Fellows participant

Speakers Bureau

Connecting scientists with students and public audiences has been the Speakers Bureau's hallmark for more than twenty years. By sharing information and creating reflective dialogue about medical research we increase interest in careers, strengthen trust in the research we promote and inspire scientists to reflect on the public implications of their work.

- Mercy Laurino, CGC and PhD candidate helped launch genetic services in her native Phillipines. Lupe Salazar, MD honors both her migrant farming beginnings and patients in her oncology practice as crucial elements of her career. These remarkable women shared their humble roots and transformative career paths with 160 community members and students, urging them to consider the value of higher education.
- Christof Koch, PhD, shared his work on consciousness and artificial intelligence with a record breaking crowd of 170 public science enthusiasts at a Seattle science café (http://kcts9.org/education/science-cafe/consciousness).
- **Heather Sidener**, DVM presented compelling evidence in favor of animal research to neighborhood pub-goers at Science on Tap: there is no safe, ethical alternative.
- Magda Moutaftsi, PhD teased out noteworthy issues within the Ebola novel, <u>The Hot Zone</u>, for students at Two Rivers School in North Bend, WA. It's one of her favorite books and she was "delighted to share it, and had a lot of fun."
- Chris Fox, PhD, wowed Jr. Science Café students at Cleveland High School, with vials of vaccine adjuvant during his interactive presentation about bioengineering vaccines. When asked why he makes the time for outreach, Chris said "I think this is very useful for high school students (and us engineers). In the past, engineering seems to have been neglected as a subject during the high school years or only targeted to the math whiz type. However, bioengineering is a very exciting and diverse field that involves unique skills, and attracts more minorities and women than traditional engineering fields."

Extremely enlightened participants and enlightening discussion!! How can we spread this phenomenon?!

Sue was a dynamic speaker and handled student discussion extremely well. What a joy to see the students finally connect to the human nature of science/medical research and to hear some of my students who have never spoken outright in class to do so easily with Sue's presentation.

Educator







Bioinformatics Program Summary

Now in its third and final year, our NSF-funded bioinformatics education program Bio-ITEST: New Frontiers in Bioinformatics and Computational Biology provided secondary science teachers with rigorous and up-todate curricular resources and support, reaching 200 new teachers from around the country through our professional development workshops and regional and national education conferences. NWABR connected teachers with scientists from our partner and member institutions like Novo Nordisk and the Institute for Systems Biology in order to provide unique opportunities for teachers to dialogue with scientists; for many teachers, this may be their only opportunity to interact directly with scientists, and bring those experiences back to their students. This program has had an impact on how teachers communicate with each other and with their students: teachers have grown their community of practice, dialogue with each other at annual reunions and participate in our online community, and inspire their students to pursue sciencerelated careers. The Bio-ITEST research study demonstrated sustained gains among teachers throughout the school year in the areas of science career awareness and self-efficacy in using bioinformatics tools and databases in their classrooms. After experiencing our Introductory unit, Using Bioinformatics: Genetic Testing, students showed significant gains in their awareness of science careers and self-efficacy using bioinformatics tools. According to the external evaluation team, "The Bio-ITEST project clearly adds to our body of knowledge on strategies to prepare young people to enter the STEM workforce of the future." The program plans to build on these findings and the work of our Emerging Role of Science Teachers in Facilitating STEM Career Awareness study through dissemination and scale-up efforts in the coming year.

I didn't know how to pass on science career info before but have a platform to teach it now through this curriculum. I feel more confident in being able to advocate for students to pursue a science career.

Bio-ITEST Teacher

Junior Science Cafes'

Imagine dozens of hands in the air, wiggly bodies barely staying in their seats, and lots of little personal vignettes shared by 3rd, 4th and 5th grade students in Coeur d' Alene, Idaho on topics related to health and biomedical research. Now imagine a small group of these same students taking leadership roles to create the events — junior science cafes — that brought their peers together for these discussions. Providing opportunities for these very young students to discuss science in informal settings, ask questions of interest to them, and develop leadership skills for student organizers were the goals of this unique collaboration between NWABR and the Idaho Idea Network for Biomedical Research Excellence (INBRE).

We believe that inspiring the next generation of citizens and scientists through programs like junior science cafés is a vital part of NWABR's mission to strengthen pubic understanding of biomedical research through education and dialogue. At Ramsey Magnate School of Science the elected student council representatives in grades 3, 4 and 5 took ownership of the junior science cafes at their school, gave presentations about each event to their classmates, created flyers and posters, introduced the speakers, took photos, wrote articles for their school newspaper, set up each event, and worked with the NWABR and INBRE staff to evaluate the program and plan future sessions.

Ultimately, the impacts of NWABR's junior science cafes go beyond the more than 200 students who asked their questions, wiggled in their seats and contributed their own stories. Not only did these students learn a bit about science, they interacted directly with scientists, learned about what scientists do every day in their laboratories, and gained a sense of the level of commitment scientists have toward making the world a better place. Perhaps the most important measure of success is that the kids have asked us to come back!

44 Over the past few years I have truly enjoyed and benefitted from the experiences that NWABR has given me. I appreciate the time you invest in organizing professional development that is worthwhile, educational and makes me feel like a professional. I have valued the opportunities to speak with researchers, doctors and other science professionals about science. I love to actually witness science happening instead of just reading about science in books. The professional development has made me a better teacher because I can share my first hand experiences with my students and make science come alive for them too. NWABR listens to my feedback and the feedback of others to ensure that their professional development opportunities are worthwhile to teachers and that is exactly why I keep returning to events. Thanks for everything you do!!!

Shani Neamen, science teacher

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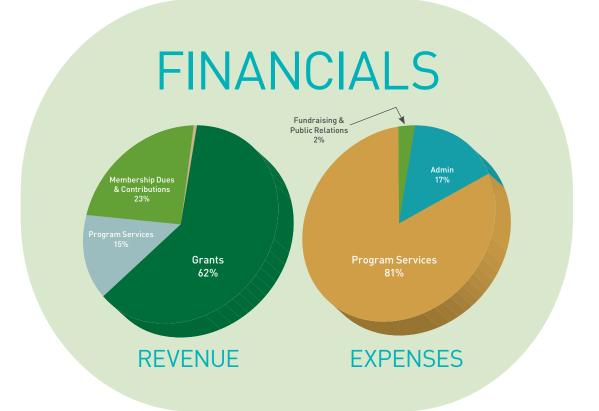
Professor and Chief, Division of Bioethics and

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NOTE:

Shades in revenue graph look too close, so looks like misshapen bubble.

Graph content should come by next week for Final.



Fund Balance as of 9/30/10

GRANTS	\$ 711,161	62%
PROGRAM SERVICES	\$165,577	15%
MEMBERSHIP DUES & CONTRIBUTIONS	\$265,992	23%
OTHER	\$ 4,225	0%

EXPENSES: \$1,166,487

ADMIN	\$193,128	17%
PROGRAM SERVICES	\$943,925	81%
FUNDRAISING & PUBLIC RELATIONS	\$ 29,434	2%

"We completed the audit of Northwest Association for Biomedical Research's financial statements for the year ended September 30, 2010 and issued an unqualified (clean) opinion." — Chris McGinness, CPA; Huebner, Dooley & McGinness, P.S.

2011 NWABR STAFF

Susan Adler — Executive Director
Jeanne Ting Chowning, MS — Director of Education
Brian Glanz — Creative Technologies Manager
Joan Griswold, MIT — Curriculum Design Lead
Laurie Hassell — Regional Manager
Nylkhalid Jungmayer — Executive Assistant

Dina Kovarik, MS, Ph.D. — Program Manager, Bioinformatics
Visa Marong — Operations Manager
Jennifer Pang, Ph.D. — Program Manager, Student Bio Expo
Leena Pranikay — Education Outreach Coordinator
Reitha Weeks, Ph.D. — Program Manager, Science Outreach
Jennifer Wroblewski, MPH — Program Manager, Public Engagement

ABOUT NWABR

Over twenty years ago, the Presidents and CEOs of our most respected research facilities recognized that public trust in the integrity of research was essential to the future of medical discovery in our region. NWABR was born out of that commitment and stands today as the Northwest's leading voice for understanding biomedical research and its ethical conduct. Through education and dialogue, NWABR is dedicated to strengthening public trust in research. Our diverse membership spans academic, industry, non-profit research institutes, health care, and voluntary health organizations.

CORF VALUES

Respect for Life.

We respect all living things.

Responsibility

We affirm that the responsible conduct of biomedical research requires continuous development of, and adherence to, safe and ethical practices.

Education

We recognize that understanding ethics and the life sciences empowers individuals and society to make informed decisions about biomedical research.

Service

We affirm that serving the needs of the scientific and educational communities advances research and improves public health.

Community

We recognize that scientific, patient, and educational communities are necessary voices in building public understanding and support for biomedical research.