2024

Pacific Northwest Research Institute

ANNUAL REPORT

OCTOBER 1, 2023 - SEPTEMBER 30, 2024

bold breakthroughs

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letter from the CEO

Dear friends, colleagues and supporters,

As I think of my experiences here at PNRI over the past year, two phrases keep tumbling through my mind: “Now more than ever!” and “We’re so close!” Both deserve exclamation marks to emphasize their importance. Now, more than ever, the research and discovery undertaken at PNRI and other institutions across the country—and around the world—need and deserve our support. Writing this letter in March 2025, traditional sources of funding are being cut while the need and value of scientific research are greater than ever. Whether research is in pursuit of new therapies for rare but calamitous genetic diseases, understanding the causes of extreme weather events, or developing sources of clean energy that are abundant and affordable.

And we are so close! Because of advances in technology that enable us to see things never seen before, computational capabilities that allow us to analyze phenomena of staggering complexity, and the general advancement and accessibility of scientific knowledge, in so many fields we are on the brink of previously unimaginable possibilities.

I also think about what it takes for a research institute such as PNRI to deliver on its potential. Brilliant scientific leadership, of course—and technicians, support staff, a well-equipped building, computers, electricity…a constellation of collaborators, supporters, advocates, students (who are our leaders of the future), and a society that understands and values science.

Science is truly a colossal and invaluable human enterprise. And what do we get from our investments and support? Obviously, not every research project leads to a breakthrough. Which ones will do so is fundamentally unknowable. But even a negative finding has value.

And when we do succeed, the benefits are spectacular. The discovery of insulin over a century ago took type 1 diabetes from being a death sentence for children to making a long, productive and happy life an achievable reality. Sometimes, as in the case of insulin or the eradication of smallpox, the change is sudden and transformative. In other cases, progress is incremental where relatively small advances in treating cystic fibrosis, for example, have extended life expectancy by 45 years since 1950.

The profound thing to comprehend is this: the benefits of these discoveries go on forever. For generations and generations to come, without limit. Science is a marvelous and life-changing human enterprise. I welcome your thoughts, suggestions and support. I can be reached at jfaris@pnri.org.

Warmly,
Jack Faris, PhD
PNRI Chief Executive Officer

2024

pnri *by the numbers*

- Published 24 studies + articles
- Produced 6 podcast episodes
- Trained 10 interns
- Welcomed 6 new board members
- Hosted 11 *Science Matters* seminars
- Led 1 hackathon

"2024 was an amazing year at PNRI because new leadership brought a renewed sense of optimism. Our scientists are all engaged in the pursuit of science that will make a meaningful difference in the lives of countless individuals and families.

There is nothing more important or gratifying than to see the great momentum that exists right now at PNRI."

Gary Kocher
PNRI Board President

2024 year in review

SCIENTIFIC HIGHLIGHTS

Advancing Rare Disease Research

Rare disease research continued as a cornerstone of PNRI's work in 2024, with significant advancements from the Dudley Lab and Carvalho Lab.

The Dudley Lab made remarkable strides in diagnosing rare urea cycle disorders. The lab developed a groundbreaking genetic screening tool for OTC deficiency—the most common urea cycle disorder—which allows clinicians to rapidly diagnose and assess the severity of the disease. The lab also made important discoveries about Argininosuccinate lyase deficiency (ASL deficiency), showing how specific genetic changes disrupt the function of a key enzyme and how certain combinations of these changes can unexpectedly restore its activity. These advancements are improving the accuracy and speed of diagnosis and bringing new hope to patients and families affected by these life-threatening disorders.

In 2024, Dr. Aimée Dudley, PNRI Interim Chief Scientific Officer and Senior Investigator, was appointed Co-Editor-in-Chief of PLOS Genetics, a leading open-access journal advancing genetic research. This role highlights Dr. Dudley's commitment to open science, which is crucial for rare disease research.

This year, the Carvalho Lab made extraordinary progress in uncovering the genetic causes of rare diseases, focusing on complex genomic rearrangements–particularly those involving developmental delays, neurological disorders, and bone malformations–often missed by standard testing methods. By developing advanced techniques to analyze these intricate DNA changes, the lab provided answers to families with previously undiagnosed conditions, paving the way for improved diagnostics and treatments.

PNRI's groundbreaking research in rare diseases also gained international recognition at global conferences in 2024. Dr. Aimée Dudley presented her lab's discoveries on urea cycle disorders, including insights into ASL deficiency and the development of the genetic screening tool for OTC deficiency. Dr. Cláudia Carvalho shared her work on complex genomic rearrangements, further showcasing PNRI's leadership in uncovering the genetic mechanisms behind rare conditions and fostering global collaboration to advance research and clinical care.

Bringing Science to Life Through a New Podcast

In 2024, PNRI launched ***PNRI Science: Mystery and Discovery***, a podcast hosted by Dr. Jack Faris and introduced by his daughter, actor/producer Anna Faris. This engaging series invites listeners to explore the passion, people, and breakthroughs driving genetic research. Each episode features conversations with PNRI scientists as they discuss their work, the challenges of uncovering genetic mysteries, and the discoveries that advance human health.

With its conversational tone and focus on accessibility, the podcast makes cutting-edge science relatable and inspiring for a broad audience. Whether you're a seasoned researcher or simply curious about how genetics shapes our world, the podcast showcases PNRI's dedication to making science available to all.

Breakthroughs in Cancer Research

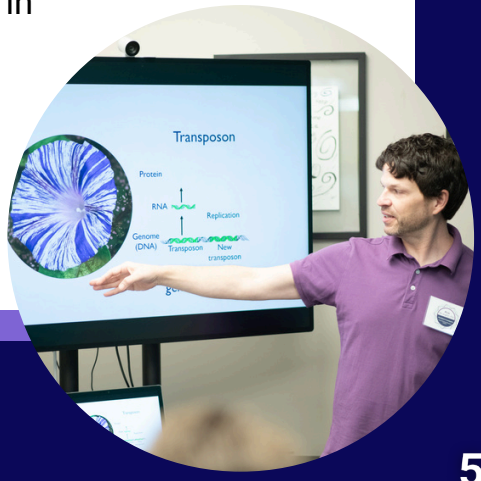
Dr. Michael Metzger and his lab's groundbreaking research into contagious cancer in clams continued to make waves in 2024, offering unprecedented insights into cancer biology. They uncovered how these cancers spread through the transfer of living cancer cells between clams, a process previously thought impossible in animals. Dr. Metzger's work was also featured at the WA Tech Alliance's Discovery Series, where he discussed its broader implications for science, health, and the potential development of innovative therapies.

Celebrating 20 Years of the TEDDY Study

This year also marked the 20th anniversary of the TEDDY Study (The Environmental Determinants of Diabetes in the Young), an international effort with PNRI serving as the only TEDDY research center on the West Coast. Over the past two decades, TEDDY has followed thousands of children at high genetic risk for type 1 diabetes, collecting extensive data on diet, infections, stress, and other environmental factors. Our final study participant came through our clinic in February 2025. These efforts have provided groundbreaking insights into how genetics and environment interact to trigger type 1 diabetes, paving the way for prevention strategies and a deeper understanding of autoimmune diseases.

Exploring the Dark Side of the Genome

In 2024, Dr. Rick McLaughlin and his lab at PNRI delved deeper into the enigmatic “dark side” of the genome—the 98% of human DNA previously labeled as “junk.” Focusing on viral genes embedded within our DNA, the McLaughlin Lab uncovered how these elements influence key biological processes and may contribute to diseases like lupus and cancer. By investigating the role of these ancient viral remnants in pregnancy outcomes and fetal development, Dr. McLaughlin’s work is reshaping our understanding of how the hidden portions of our genome impact health and disease, paving the way for innovative approaches to diagnosis and treatment.



Hosting Events to Build Community & Collaboration

In October 2023, PNRI hosted an unforgettable night at AXIS Pioneer Square, for our Bold Breakthroughs donor gala. The highlight of the night was a moving panel discussion with PNRI Senior Investigator Aimée Dudley, PhD, Andrea Gropman, MD, of Children's National Hospital, and Tresa Warner, president of the National Urea Cycle Disorders Foundation (NUCDF), facilitated by Jessie Hastings Conta, owner of Pickhandle Consulting and a licensed genetic counselor.

With their individual expertise as scientist, clinician, and advocate, the panelists discussed a recent breakthrough from the Dudley Lab: A novel technology that is now revolutionizing how a life-threatening urea cycle disorder called OTC deficiency is being diagnosed. Bold Breakthroughs was an incredibly meaningful event as we reconnected our community and raised funds for the future of our research.

In February 2024, PNRI's Science Matters seminar in honor of Rare Disease Day featured two influential voices in the rare disease community: Jill Hawkins, Founder and President of the FAM177A1 Research Fund, who shared her family's journey from undiagnosed children to building a scientific network, and Dr. Jennifer Posey, Physician Scientist at Baylor College of Medicine, who introduced the BCM-GREGoR program and its recent discoveries in accelerating molecular diagnoses for rare disease families.

In May, PNRI hosted its inaugural Rare Disease Hackathon, bringing together researchers, clinicians, and data scientists from around the globe to tackle unsolved challenges in rare disease genetics. This innovative event demonstrated the power of cross-disciplinary collaboration and set the stage for future problem-solving initiatives at PNRI.

PNRI also opened our doors for lab tours, offering a unique opportunity for attendees to engage directly with our scientists, explore state-of-the-art technology, and learn about the groundbreaking work being conducted at PNRI.

Thank you to our Bold Breakthroughs sponsors!

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PNRI's Year of Groundbreaking Publications

PNRI scientists published an impressive 24 studies and articles in 2024, advancing our understanding of genetics and disease across a wide range of topics. These publications, available on our publications page, reflect the depth and impact of PNRI's research efforts over the past year.

Training the Next Generation of Scientists

The Summer Undergraduate Research Internship (SURI program) at PNRI provides undergraduate students in an array of scientific disciplines the chance to work in a state-of-the-art research lab. Interns build skills and lead a research project under the mentorship of postdoctoral fellows and our Principal Investigators (PIs), who helm each of our labs.

Summer 2024 marked a milestone for PNRI with ten students joining us in the labs, the largest cohort of interns we have ever hosted. We are honored to expand this program and include more talented young people in the opportunities available at our institute.

donor roll

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Includes supporters who purchased tickets to Bold Breakthroughs at the end of FY23, and those who donated to our end-of-year campaign during the first quarter of FY25.

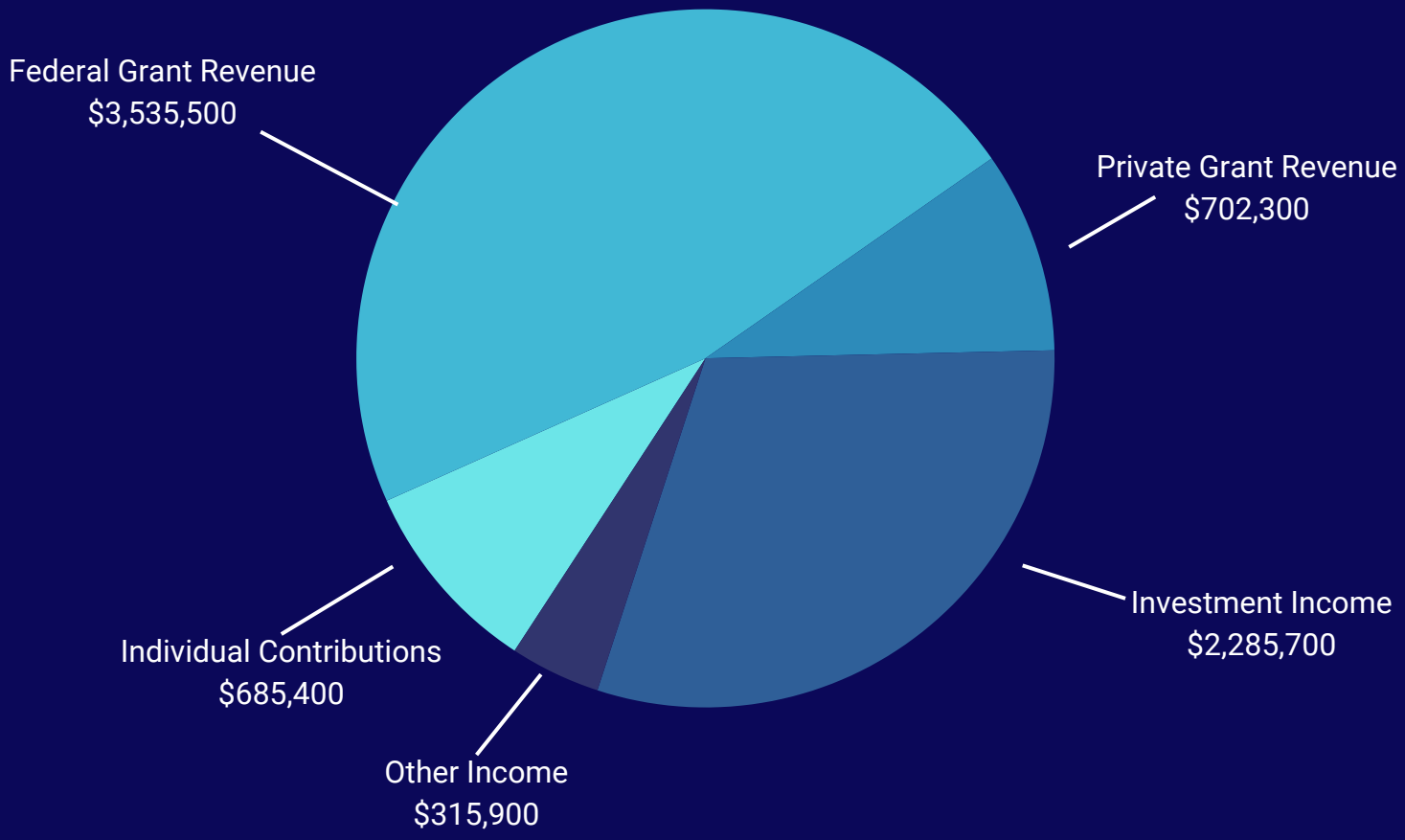
financials

FY2024

OCTOBER 1, 2023 - SEPTEMBER 30, 2024

(not audited, rounded to the nearest $100)

Revenue



Financial Position

Total Assets: $13,215,800

Total Liabilities: $886, 200

Net Assets: $12,329,600

looking ahead

PNRI's growth this year extended to its leadership, with seven new trustees joining the board. Their diverse expertise in science, business, and advocacy will help guide the institute as it continues to push the boundaries of genetic research.

"We are preparing to celebrate the 70th anniversary of our founding by Dr. William Hutchinson, a physician and scientist of great vision and dedication. But even he could not have imagined in 1956 that today our work would be enabled by decoding the human genome, supercomputers, electron microscopes, AI, and other advancements.

We look forward to what will be possible when we celebrate our 80th, knowing that we can only dimly imagine what will be achieved by then, but with confidence that the achievements of the decade to come will deliver better health to people everywhere."

Jack Faris, PhD
PNRI CEO