ANNUAL REPORT 2022

JANUARY 1-DECEMBER 31



Together, we are making a **difference.**



AUTISM RESEARCH INSTITUTE Autism is Treatable

ABOUT



One-of-a-Kind Research and Educational Institution



I am honored to work on behalf of persons and families touched by autism by serving on the ARI Board of Directors and the ARI Scientific Advisory

Board, and in doing so, supporting research and education."

Marvin Natowicz, MD, PhD ARI Chairman of the Board

Our Mission

The mission of the Autism Research Institute is to support the health and well-being of people affected by autism through innovative, impactful research and education.

Our Community

Earlier this year, the Centers for Disease Control announced that about 1 in 36 children has been identified with autism, according to estimates from the Autism and Developmental Disabilities Monitoring (ADDM) Network.

Our Commitment

ARI continues to fund research, support educational programs, and provide information and resources to the autism community.



Bernard Rimland, PhD 1928-2006

Autism is now recognized as a neurodevelopmental condition. This was not always the case.

One man stood against the prevailing views and changed public and medical opinion. This man, Dr. Bernard Rimland, became a one-stop center for those who needed help and information. His legacy lives on in The Autism Research Institute. For several decades, ARI has given a voice to autistic individuals in myriad areas at a global level."

Manuel F. Casanova, MD ARI Scientific Advisory Board Member

Inside this Report

Learn about the programs ARI funds and supports:

- Autism Tissue and Data Banks
- Autism Treatment Effectiveness Checklist (ATEC)
- Consensus Meetings and Reports
- Global Researcher Network
- Global Support Network
- National Autism History Museum
- Online Education
 - Clinical Webinars for Healthcare Professionals
 - Continuing Medical Education for Professionals
 - Educational Webinars for Parents and Professionals
- Our work as a United Nations Registered Non-Governmental Organization (NGO)
- Printed and Online Publications
 - Autism Research Review International
 - Books on Autism Research and Treatment
 - E-Newsletters
- Scientific Research Grants
- Think Tanks and Scientific Meetings



Autism is Treatable

AUTISM RESEARCH INSTITUTE

Message from our Executive Director and Chairman of the Board

Dear ARI supporter,

Our long-standing commitment at the Autism Research Institute (ARI) has always been to enhance the health and well-being of those impacted by autism, and we do this through pioneering research and education. We are deeply appreciative of your trust in our organization and our



Stephen M. Edelson, PhD Executive Director

mission. Your support has been instrumental in our continued growth and the expansion of our network, and the initiation of innovative programs and projects that further both autism research and our educational efforts.

Our path has seen significant evolution, yet our core mission — initially articulated by Dr. Bernard Rimland's vision of a global institute devoted to autism — remains steadfast and unaltered. We have fostered a community of innovative scientists, devoted clinicians, and committed parents, all with a shared purpose: to develop effective strategies and provide critical support to autistic individuals and their families.

We currently join forces with forward-thinking professionals and distinguished research centers, including Harvard/Massachusetts General Hospital, Boston University, the MIND Institute and many others known for their unwavering commitment to quality research. In addition to supporting researchers both within the United States and internationally, we have numerous outstanding education programs for families throughout the world, as well as education programs for health professionals in the U.S. and abroad. ARI is a non-governmental organization, registered with the United Nations.

Looking back over the past year and our organization's illustrious history, we take pride in ARI's impact. We encourage you to share in our pride as you review our achievements in the Annual Report. This report acknowledges the combined efforts of our Board of Directors, Scientific Advisory Board, staff, and above all, the autism community.

We are grateful for your continued support and for being a significant part of our journey. Thank you.

Sincerely,

Stephen M. Edelson, PhD Executive Director Autism Research Institute

Stell M. Slobon Marvin Naturicz

Marvin Natowicz, MD, PhD Cleveland Clinic Chairman of the Board, ARI



ARI Touches Lives

We work every day to provide the research, education, and treatment advocacy that is urgently needed.

> My son Jaxson is a superhero! He has made tremendous progress through Applied Behavior Analysis, occupational therapy, speech therapy, and appropriate medical support. Everyone who has invested their time in him has helped him grow into the amazing superhero he is today!"

> > Nici Petrich Sioux Falls, SD





Brilliant and so helpful! I am a therapist diagnosed autistic at 63, so this work is really important to me professionally and personally. Big thanks!"

> **Felicia Libo, MA, LPC** Durango, CO

ARI was one of my first sources of information when my son was diagnosed in 1988. Today, I find the webinars to be a good resource. Bobby has a small business making habitats for native bees. He entered a mason bee house in a local Interstate Fair and received a ribbon."

> **Julie Parry** Spokane, WA



We bring the latest research to professionals who work with people with autism.



Dr. Supekar's presentation was excellent, thoughtful, respectful, and compassionate with regard to the population and the work that still needs to be done. Great work, thank you."

> Karen A. Saporito, PhD Clinical psychologist specializing in ADHD and autism, with a focus on females



WEBINAR: Behavioral and Brain Signatures of Autism in Females



Kaustubh Supekar, PhD Clinical Assistant Professor Stanford University School of Medicine

Thank you for this important information. I am a Registered Nurse working to support adults with IDD-MH. I will share this information with my colleagues."

> Diane G. Carter, RN Lancaster, NH





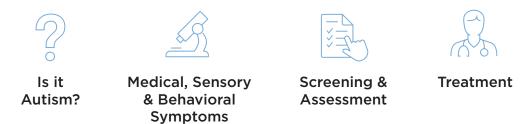


ARI Supports Broad Areas of Research

ARI Advocates for Research That Makes a Difference

Our focus at ARI is to support innovative autism research while providing the latest science-based information for people of all ages on the autism spectrum. We do this through our annual and regional Think Tanks, in-person and online educational events and courses, free webinars, and by funding the studies that hold the most promise for making a difference in the lives of people with autism.

While the causes of autism in the vast majority of individuals remain unclear, scientific advances challenge the traditional view of autism as an untreatable disease — as one that is genetically hardwired. These developments support the position that ARI has always maintained: *Autism is Treatable*. ARI continues to pioneer research, outreach, and cooperative efforts with other organizations worldwide.



Think Tanks: ARI Convenes Scientists and Clinicians Face to Face

Since 1995, the Autism Research Institute has brought together experts at its annual scientific Think Tank meetings to address novel questions and discuss issues related to promising interventions. ARI also funds and sponsors consensus meetings to facilitate ongoing discussions about the latest findings and approaches to understanding and treating medical and behavioral symptoms associated with autism spectrum disorders.

We have always been committed to asking the tough questions. For more than 50 years, our work has influenced how researchers approach investigating the causes of and effective treatments for autism.

Our purpose is clear: Advance research by following the science wherever it leads.

ARI Creates Free Online Continuing Education on Autism for Physicians and Other Healthcare Providers

ARI works in partnership with leading experts to provide professional education that gives thoughtful, inquisitive clinicians the means to offer support to individuals with autism that is safe and effective.

Informing physicians about appropriate standards of care is crucial to our mission — in joint providership with the Cleveland Clinic we continue to offer complimentary CME-certified online education to amplify understanding of the medical nature of autism. All internet users can view the *Autism Spectrum Disorders: Research and Medical Treatment Implications* webcast series for free online. Learn more at Autism.org/CME

New series released November 2022:

Gastrointestional Conditions in Autism, Medical Challenges Associated with Aging and Autism, and Improving Healthcare Access for Patients with Autism



Paola Bonsi, PhD and Valerio Chiurchiù (front) with PhD students/postdoctoral scholars working on the project: Martina, Maria and Marta (left to right).

Thanks to the support from ARI, we have the opportunity to investigate a non-pharmacological strategy aimed at reducing neuroinflammation in the brain."

> **Paola Bonsi, PhD** Fondazione Santa Lucia

Global Researcher Network

ARI continues to develop a Global Researcher Network to keep researchers up to date with the latest news in the scientific community; this includes sharing articles on conducting research, informing them of various funding sources, and notifying them of the latest studies published in peer-reviewed journals.

ARI Collaborates to Support Tissue Donation

Tissue research is needed to understand the underlying causes and potential treatments for autism. ARI assists two tissue banks: a brain tissue bank for the National Institute of Child Health and Human Development at the University of Maryland and a gastrointestinal tissue biorepository at the Digestive Function Laboratory Repository at Massachusetts General Hospital in Boston.

ARI Facilitates Expert Consensus Reports

ARI is facilitating the collaboration among distinguished researchers and clinicians to write summary reports on known findings as well as areas requiring further investigation regarding co-occurring medical issues related to autism, including:

- Gastrointestinal
- Genetic
- Immunologic
- Metabolic
- Neurological
- Neuropathological
- Nutritional
- Sleep

ARI Supports Research on Aging and Autism

ARI's leadership actively participates in a group of international researchers focused on improving the quality of life and healthcare experiences for seniors with autism and/or intellectual disability spectrum. As part of this effort, ARI is co-sponsoring an international think tank on aging planned for late 2023.

We are also conducting an online survey of seniors to collect data about autism throughout the entire lifespan. We hope the results will provide insight into the needs and challenges of seniors with autism (aged 50 years or older) and their support providers. For more information, see: ASDSeniorSurvey.com



ARI Supports Broad Areas of Research

In 2022, ARI awarded more than \$450,000 in research grants to scientists whose work will have a direct impact on the lives of individuals diagnosed with autism.

To read more about these studies, please visit: Autism.org/ARI-funded-research-studies-2022



miRNA as a Potential Mediator in Maternal/Fetal Interaction in Neurodevelopmental Disorders

David Beversdorf, MD University of Missouri



Impact of Environmental Enrichment on the Resolution of Inflammation in a Mouse Model of Autism Spectrum Disorder

Paola Bonsi, PhD Fondazione Santa Lucia



Understanding Role of Peroxynitrite Signaling and Developing Therapeutic Intervention for Autism Spectrum Disorder

Adrien Eshraghi, MD, MSc, FACS University of Miami Hearing Research and Communication Laboratory





Placental Trophoblast Inclusions as Autism Risk Markers Among Preterm Infants

William Fifer, PhD, Principal Investigator Morgan Firestein, PhD, Co-Investigator Columbia University Irving Medical Center



Zinc Nutrition as Key Regulator of Inflammatory Gut-brain Signaling in Autism

Andreas Grabrucker, PhD University of Limerick



Discovery of ASD Related Pathways in a Novel Preterm Rhesus Macaque Maternal Immune Activation Model

Suhas Kallapur, MD University of California Los Angeles



Rescue of a Neurodevelopmental Disorder Associated With ASD by Induction of the Heat Shock Response

Andrew Levy, PhD Technion Israel Institute of Technology



Characterizing Auditory Sensory Stability in Autism

Adam Naples, PhD Yale University



Randomized Placebo-controlled Double-blind Cross-over Study of Coenzyme Q10, Vitamin E and Polyvitamin B in a Cohort of Individuals With Autism Spectrum Disorder

Antonio M. Persico, MD University of Modena and Reggio-Emilia (Modena, Italy)



Testing Cannabinoid Type 2 Receptor (CB2R) as a Potential Therapeutic Target in ASD: a Pilot Study on a Mouse Model of Maternal Immune Activation

Anna Maria Tartaglione, PhD Istituto Superiore di Sanità (ISS), Italy



Home-based Measurement of Autonomic and Endocrine System Function and Relations to Sensory Processing in Children With and Without Autism

Jennifer Wagner, PhD CUNY College of Staten Island



Is There a Relationship Between the Gut Mucosal-associated Microbiome, Intestinal Neurotransmitters and Behavior in Individuals on the Autism Spectrum?

Harland Winter, MD Massachusetts General Hospital

Announcing the Robert L. Hendren Research Grant Award

In honor of his many years of support for our work, serving as a member of the Scientific Advisory Board and Board of Directors, we are pleased to announce that the top-scoring research grant proposal funded each year will be recognized as the Robert L. Hendren Research Grant Award starting in the fall of 2023.





ARI Provides Everyone Access to Resources

ARI Democratizes Learning through Online Webinars

ARI makes an effort to provide presentations that are unbiased and broad-reaching, and to assist families and professionals in making informed treatment decisions. We also strive to provide professional education that enables clinicians to offer support to individuals and their families.

Learn more at AutismWebinars.org

Users have tuned in for nearly 1 million viewings.





Depth of knowledge; easy to understand

I really appreciate the depth of knowledge displayed in the presentation. It was very detailed, so it made for easy comprehension of the material. Thank you so much, and keep up the excellent work that you have been doing."

Sharon Perry Parent Philadelphia, PA

Webinars share classroom strategies

This was an excellent webinar. I am always looking for new language to use in my classrooms. I definitely walked away with a few new ideas and concrete must-dos."

Della Orcutt Autism Consultant Roseburg, OR

ARI's Online Presence Expanded

During the pandemic, we broadened our online presence through our website, online tools, live webinars, and continuing-education offerings and we facilitated our first online ARI Scientific Meeting.

6,505 + 134,053 + 2,384 live webinar participants

webinar plavbacks **Continuing Medical** Education credits



WEBINAR TOPICS 2022

Continuing Education

Topics included:

Gastrointestional Conditions in Autism

Improving Healthcare Access for Patients with Autism

Medical Challenges Associated with Aging and Autism

Webinars for Parents and Professionals

Assessing and Treating **Challenging Behavior**

Autism and Eating-Related **Behaviors**

Back-to-school Strategies

Behavioral and Brain Signatures of Autism in Females

Clinical Approaches for a Gluten-/Casein-free Diet

Creating a Well-Structured Classroom for Students with Autism

Disruptive Mood Dysregulation Disorder in Young Adults

Emotional Regulation Strategies

Evidence-Based Strategies to Support People as They Transition into Adulthood

Executive Functioning -Strategies at Home

Gender Differences in Autism -Delayed and Misdiagnosis of Autistic Females

Metabolic Considerations in the **Evaluation of Autistic Individuals**

Optimizing Preconception Health Through Nutrition

Pet Ownership and Autism

Sensory-Friendly Strategies for Home

Ukrainian Support Panel - 1 & 2

Quarterly Webinars in Partnership with the World Autism Organisation

Autism and Pica

Challenges of Medical Care for Seniors

Plural "Autisms" and the Promises of Autism Metabolomics

Understanding and Treating **Challenging Behaviors**

ARI Offers a Free Online Assessment Tool: Autism Treatment Evaluation Checklist (ATEC)

Researchers have published thousands of studies attempting to evaluate different biomedical, behavioral, and educational interventions intended to benefit those with autism. The Autism Treatment Evaluation Checklist was developed by Dr. Rimland and Dr. Edelson to serve as a means to assess the effectiveness of interventions for those with autism. Since its inception, hundreds of thousands of ATEC forms have been completed.

ARI Publishes Articles and Books on Critical Topics

Autism Research Review International

From early days, ARI updated the autism community about research in the areas of behavioral, education, genetic, medical, and sensory issues. To that end, in 1987, ARI began publishing a quarterly science newsletter, the *Autism Research Review International*. Besides reporting on the most current and relevant research findings, the newsletter includes editorials on important insights and perspectives in the field. For many, this newsletter is an important source of trusted information about science and autism.

Books Featuring Insight from Leading Autism Experts

ARI began with the publication of our founder Dr. Bernard Rimland's seminal book, *Infantile Autism*, and we have published numerous books over the decades since, featuring contributions from pioneering researchers and clinicians in the field. ARI's latest book series, *Understanding and Treating Autism*, provides a professional understanding of the impact of co-occurring medical conditions and autism.

Remembering Our Past... While Always Moving Forward

In early 2023, ARI announced the opening of the National Autism History Museum. This new effort offers an engaging and comprehensive look at the prolific history of autism research and discovery, showcasing significant scientific breakthroughs and milestones over the last century that fundamentally changed how we understand and treat autism.

We cannot build upon the future without learning about the triumphs and mistakes of the past."

Stephen M. Edelson, PhD

Autism Research Institute Autism History Museum

ARI Actively Engages with its Community

Autism.org and Social Media

We post updates and information to our website and on social media, including descriptions of recent research studies and important autism-related news.

Vale and a Mary

Contraction of the second

UNDERSTANDING

AND TREATING

NXIETY IN AUTISM

Toll-free Telephone Hotline: 833-281-7165 ARI offers a free hotline for parents and professionals.

E-newsletters

ARI publishes the monthly *ARI E-newsletter* for more than 143,000 subscribers and *Clinical Research in Autism*, a bimonthly e-newsletter sent to more than 10,000 obstetricians, pediatricians, and nurses to keep them informed on research relevant to their practice.

Subscribe:

Autism.org/ari-monthly-e-newsletter Autism.org/clinical-research-e-newsletter

ATEC in 2022

- Nearly 75,000 ATECs completed
- >200 completed per day in 2022
- Now available in 25 languages



GLOBAL



ARI's Impact and Presence is Worldwide



Dr. Stephen M. Edelson presenting in France in 2022.

Our Worldwide Impact

228 Groups77 Countries25 Languages

ARI Conducts International Outreach and Translates Resources

ARI is a non-governmental organization (NGO) that provides educational resources and tools to users worldwide. Outreach includes targeted efforts working with network groups and clinicians worldwide, especially in regions where awareness and support are still emerging, such as areas of Eastern Europe and South America.

ARI's Global Support Network connects with 228 groups in 77 countries, including Argentina, Belgium, Croatia, Egypt, Germany, Israel, Moldova, Nigeria, Peru, Poland, Romania, Spain, Switzerland, Ukraine, Venezuela, and Vietnam.

ARI also offers a telephone support line for caregivers, and translates many of its online articles, as well as the Autism Treatment Evaluation Checklist (ATEC). ARI's ATEC is offered for free, online, in 25 languages, including Chinese, Vietnamese, Hebrew, Lithuanian, Romanian, and Czech – and more than 200 users per day use this tool.

It feels so liberating.

Excellent presentation. (*Delayed and Missed Diagnoses of Autistic Women*, Nov. 2022.) It feels so liberating to hear evidence-based research on everything an undiagnosed woman with autism has been going through for almost a lifetime."

Efthalia Kaderoglou Thessaloniki, Greece





I'm inspired.

Thank you for doing this for us! Most of the time we educators are tackling our 'to-do' list as best as we can. I feel like my time was valued during this clear, concise webinar presentation. So many teachers, educators and parents need this. I'm inspired."

Anarosy Torre, BCaBa Educational Consultant Guayaquil, Ecuador





Stewardship and Overview

Transparency

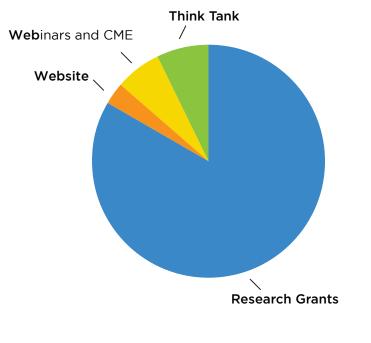
Thousands of supporters have donated to ARI over the past 56 years, sharing our values and our commitment to accomplish our mission of improving the health and well-being of people with autism.

We are deeply committed to maintaining transparency while working as efficiently as possible by sponsoring impactful autism research while educating professionals, those who are affected, and their families.

To view ARI's comprehensive financial statements, visit Autism.org/financial-information



2022 Programs and Services



2022 Financial Overview

FUNDING	
Donations and Grants	\$1,020,222
PROGRAMS	
Grants for Research	\$ 489,325
Education and Resources Think Tank Webinars Website Physicians' Training-CME	\$ 126,054
Total Program Costs	\$ 615,379
TOTAL NET ASSETS	
Total Net Assets as of Dec. 31, 2022	\$ 3,858,582

Charity ... Navigator 2023 Candid. The Autism Research Institute's strong financial health and commitment to accountability and transparency have once again earned it Charity Navigator's highest rating (4-Stars) and Candid GuideStar's highest rating (Platinum).

The Autism Research Institute is a non-profit 501(c)3 organization focused on conducting and sponsoring research aimed at improving the quality of life for today's generation of children and adults with autism. Contributions are tax deductible as allowable by law. Fed ID No. 95-2548452.





Scientists, Researchers, Educators, Parents, and Family Members

2022 Board of Directors



Marvin Natowicz, MD, PhD CHAIRMAN OF THE BOARD Scientific Advisory Board Member Cleveland Clinic Case Western Reserve University School of Medicine



James Walker TREASURER Chief Operating Officer Adams Street Partners Chicago, IL



S. Jill James, PhD SECRETARY Scientific Advisory Board Member University of Arkansas for Medical Sciences



Robert L. Hendren, DO Scientific Advisory Board Member University of California, San Francisco Medical Center



Kelly Barnhill, MBA, CN, CCN Scientific Advisory Board Member The Johnson Center for Child Health & Development



Wenn Lawson, PhD Teaching Fellow, Birmingham University, UK; Research Officer, MaQuarrie University, NSW. Australia; University of Western Australia, and Curtin University, WA



Kenneth Clayton Sassower, MD Scientific Advisory Board Member Massachusetts General Hospital; Harvard Medical School



Harland Winter, MD Scientific Advisory Board Member Massachusetts General Hospital; Harvard Medical School



Margaret L. Bauman, MD is a distinguished pediatric neurologist and investigator who has been a pioneer in the study and treatment of autism for the past 40 years. One of the world's foremost physicians in this field, she is highly respected for the outstanding clinical care she provides, as well as for her research and teachings in the domain of developmental disorders. Dr. Bauman is an Associate Professor of Anatomy and Laboratory Medicine in the Department of Anatomy and Neurobiology at the Boston University School of Medicine. She also serves on ARI's Scientific Advisory Board.

Staff



Stephen M. Edelson, PhD Executive Director



Denise Fulton Managing Director, Administration and Programs



Rebecca McKenney



Office Manager



Melanie Glock Communications and Development Specialist



Nicole Cacchiotti Search Engine Optimization and Marketing Specialist

Key Volunteer Jane B. Johnson, Think Tank Coordinator

Consultants

Chris Cava Preston, Art Direction Nataliya Vasylevskaya, International Outreach Coordinator

ARI's Scientific Advisory Board provides informed support and direction for our research initiatives. Dr. Stephen M. Edelson leads the group, assembling leaders in the medical and scientific community in order to further ARI's ongoing commitment to research that makes a difference.



ARI's Scientific Advisory Board



James B. Adams, PhD Arizona State University



Emily Casanova, PhD Loyola University



Juergen Hahn, MS, PhD Rensselaer Polytechnic Institute



Rosa Krajmalnik-Brown, PhD Arizona State University



Andrey Rzhetsky, PhD Professor of Medicine and Human Genetics, The University of Chicago



Paul Ashwood, PhD University of California, Davis MIND Institute



Manuel F. Casanova, MD



Laura Hewitson, PhD The Johnson Center for Child Health and Development



Edward Levin, PhD Duke University



Judy Van de Water, PhD University of California, Davis MIND Institute; NIEHS funded Center for Children's Environmental Health



David Beversdorf, MD University of Missouri



Bradley Ferguson, PhD University of Missouri



Mady Hornig, MA, MD Columbia University Mailman School of Public Health



Lauren Moskowitz, PhD St. John's University



Daniel Vogt, PhD Michigan State University



Robert E. Burrier, PhD Stemina Biomarker Discovery



June Groden, PhD Groden Center Providence, RI



Harumi Jyonouchi, MD Saint Peters University Hospital; Robert Wood Johnson University Hospital; Rutgers New Jersey Medical School



Robert Rubin, PhD Resident Scholar, Mathematics Department Whittier College



Marc Weisskopf, ScD, PhD Harvard University

Not pictured: Mary Coleman, MD Foundation for Autism Research



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Autism.org

Connect with the Autism Research Institute



ARI provides such a wealth of information. Their webinar presenters offer valuable insights and expertise that researchers interventionists, educators, and caregivers can pull from."

> **Leslie Hindman-Gresham** Early Childhood Special Education Teacher Parker, CO

Together we can make a difference.

Help us reach our goals. Every gift makes an impact.

\$1,000 will fund:

two webinars featuring expert presenters

Each talk serves up to 10,000 viewers in real-time with online playback offered later the same day. **\$5,000** will help fund:

think tanks

providing scientists opportunities to forge collaborations, understand the complexities of autism, and make greater strides faster. **\$15,000** will fund:

webinars for medical professionals

(complimentary continuing education)

We've supported more than 28,000 physicians and others in the past five years.

\$50,000 will fund:

Non-Profit Org

U.S. Postage

PAID LITHTEX NW

a grant for promising new research

(early-phase investigational)

ARI provided researchers with more than \$1 million in grants in the past five years.

Please use the enclosed donation envelope or visit **Autism.org/donate** to give today. *Contributions are tax deductible as allowable by law. Fed ID No. 95-2548452.*



The Autism Research Institute's strong financial health and commitment to accountability and transparency have once again earned it Charity Navigator's highest rating (4-Stars) and Candid GuideStar's highest rating (Platinum).