

LEADERSHIP FORUM



**MONDAY
JUNE 3, 2019**

Gold Room, Grand Prince Hotel

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Dear friends:

It is with great pleasure that I welcome you to the second WPC Leadership Forum. While the World Parkinson Coalition has been bringing leaders of the Parkinson's nonprofit community together since the first World Parkinson Congress in 2006, this is only the second Leadership Forum that invites leaders to join in a dedicated day-long forum before the Congress even begins. The purpose of this Forum is for you to learn, connect, and be inspired by the impactful work we are all doing across the globe and to take home ideas you can implement upon your return.

While each of our communities have different needs and face unique challenges, we share the common mission to serve people with Parkinson's and their families. The urgency with which we tackle this disease is present in the work being done in Mumbai and Mombasa just as it is with those of you in New York and London. While we may work differently due to our healthcare systems, cultural challenges or financial barriers, we all work to raise awareness, educate, and empower the community.

Today is just one day, but it's an important gathering. We would not be here without the hard work of the Leadership Forum Committee, led by co-chairs Dr. Maria Barretto and Steve Ford. The committee held many meetings to discuss the agenda, even sent out a survey or two to get your input, and after many months and many calls they created this agenda which you now hold in your hands. This gathering happens just once every three years, so I encourage you to connect, share, and stay in touch.

I want to personally thank you for making this WPC Leadership Forum a priority in your schedule and for traveling so far to be with us today. The WPC values your partnership and looks forward to building a stronger, more unified voice across the global Parkinson's community.

Kind regards,



Elizabeth "Eli" Pollard
Executive Director



AGENDA

WPC Leadership Forum

8:00 – 9:00 AM	ARRIVAL: Check in Hang posters Light breakfast EMCEE – Maria Barretto <i>(Parkinson’s Disease and Movement Disorder Society, India)</i>
9:00 – 9:05 AM	Welcome: Eli Pollard <i>(World Parkinson Coalition®)</i>
9:05 – 9:15 AM	Welcome: Genko Oyama <i>(Japan Parkinson Congress)</i> Kosei Hasegawa <i>(Japan Parkinson Disease Association)</i>
PANELS	
9:20 – 10:20 AM	PANEL 1: Reaching the newly diagnosed Chair: Emma Collins <i>(Parkinson’s Victoria)</i> Panelists: Ronnie Todaro <i>(Parkinson’s Foundation)</i> Steve Ford <i>(Parkinson’s UK)</i> Genko Oyama <i>(Japan Parkinson Congress)</i>
10:25 – 11:25 AM	PANEL 2: Finding the underserved Chair: John Lehr <i>(Parkinson’s Foundation)</i> Panelists: Leslie Chambers <i>(American Parkinson Disease Association)</i> Jo-Anne Reeves <i>(Parkinson’s New South Wales)</i> Sharmila Donde <i>(Parkinson’s Disease and Movement Disorder Society, India)</i> Natasha Fothergill-Misbah <i>(Africa Parkinson’s Disease Foundation)</i>
11:30AM – 12:30 PM	PANEL 3: Starting a Parkinson’s program and how to empower those who want to start their own organization Chair: Claudia Martinez <i>(Muhammed Ali Parkinson Center)</i> Panelists: Munal Subedi <i>(Nepalese Parkinson’s Disease Association)</i> Debbie Shapiro <i>(Tikvah for Parkinson’s)</i> Sara Lew <i>(Malaysian Parkinson’s Disease Association)</i> Tim Hague <i>(U Turn Parkinson’s)</i>
12:30 – 2:00 PM	LUNCH & POSTER DISPLAY

ROUNDTABLES

<p>2:00 – 2:55 PM</p>	<p>TABLE 1: Increasing engagement with your support groups Moderator: Malcolm Irving (<i>Parkinson's New South Wales</i>) Learning Objective: Strategies for reaching different audiences.</p> <p>TABLE 2: Building partnerships with businesses and non-profits Moderator: Dianne Stephenson (<i>Critical Path Institute</i>) Learning Objective: Strategies for identifying partnership opportunities.</p> <p>TABLE 3: Working with Government Moderator: Joyce Gordon (<i>Parkinson Canada</i>) Learning Objective: Strategies for working with government to provide education about PD and connect people with the services they need.</p> <p>TABLE 4: Finding financial support for your programs Moderator: Paul Jackson Clark (<i>Parkinson's UK</i>) Learning Objective: Strategies for revenue generation.</p> <p>TABLE 5: How do you get your message out? Moderator: Leilani Pearl (<i>Parkinson's Foundation</i>) Learning Objective: Strategies for increasing the reach of your messaging.</p> <p>TABLE 6: Expanding program reach through technology Moderators: David Leventhal (<i>Dance for PD</i>) Sarah Jones (<i>Parkinson & Movement Disorder Alliance</i>) Learning Objective: Discussing what technology can and cannot do to bring your program to more people.</p>
<p>3:00 – 3:45 PM</p>	<p>Uniting the Parkinson's community: The role of industry Moderator: John Lehr (<i>Parkinson's Foundation</i>) Panelists: Binith Cheeran (<i>Abbott</i>) Gail Cohen (<i>Acorda</i>) Sarah Mathieson (<i>Adamas</i>) Jesse Cedarbaum (<i>Biogen</i>) Alison Miller (<i>US WorldMeds</i>) Elena Nikonova (<i>Kyowa Kirin</i>)</p>
<p>3:45 – 4:00 PM</p>	<p>FINAL REMARKS Maria Barretto (<i>India</i>) & Steve Ford (<i>UK</i>)</p>

MEET THE SPEAKERS

WPC Leadership Forum

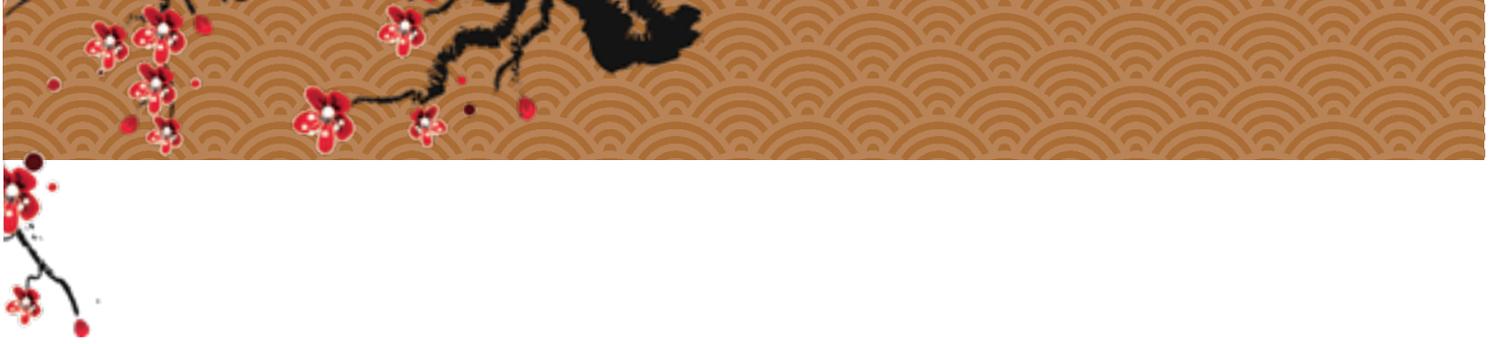
Maria Barretto, currently CEO of the PDMDS, has over 30 years of experience in the field of psychology and education. Having worked with the UNICEF, she brings a vast experience to PDMDS, and has been instrumental in taking a multidisciplinary model of Parkinson's care to the affected Indian masses in a group therapy format. In her own words, "I have been blessed with a career that gives me the opportunity to be a part of the lives of people who have been challenged in different ways. In the past 10 years of my career I have been involved in developing and managing the Parkinson's Society and I have gained much more than I have given." Dr. Barretto further adds that seeing the resilience displayed by PwPs, teaches her to not take the aspect of health for granted.

Dr. Barretto has been the face of the society, since her association with PDMDS began in 2004. She has represented the society at many international conferences and forums; and in recognition of her excellent work in improving the quality of life of individuals with Parkinson's, she has been bestowed with the Dr. Rana International Parkinson's Community Service award in 2011.

Jesse Cedarbaum obtained his medical degree from Yale Medical School, where he is currently Professor (Adjunct) of Psychiatry. After residency at New York Hospital-Cornell Medical Center Dr. Cedarbaum joined the Cornell faculty and led the Parkinson and Movement Disorders program at Burke Rehabilitation Center and the New York Hospital, from 1983-1990. Dr. Cedarbaum then joined Regeneron, where he led the establishment of the clinical development function and served as Program Director and later Vice President of Clinical Affairs from 1990-2007. He subsequently held positions at Elan, Cytokinetics, and Bristol-Myers Squibb. Dr. Cedarbaum is currently Sr. Distinguished Investigator at Biogen, leading a team focused on development of novel therapeutics for Parkinson's disease and Movement Disorders. Dr. Cedarbaum has authored or co-authored over 100 peer-reviewed scientific publications, most in the area of neurotherapeutics. He is a Fellow of both the American Academy of Neurology and the American Neurological Association. He currently is the Industry Co-Chair of the Critical Path for Parkinson's consortium sponsored by the Critical Path Initiative and Parkinson's UK.

Leslie Chambers was appointed President and CEO of the American Parkinson Disease Association in August 2012, bringing to the role a rich background in successful leadership and management experience with more than 30 years the non-profit, voluntary health sector.

During her tenure with APDA, Leslie has successfully led the organization through its first-ever strategic plan, resulting in increased patient-focused programs and services, educational initiatives and expansion of its research funding. Well into APDA's next strategic plan, Leslie continues to push APDA forward with the drive and focus necessary to fulfill its mission of helping everyone impacted by Parkinson's disease live life to the fullest. Leslie leads a team that is responsible for implementing the largest grassroots network dedicated to fighting Parkinson's disease who work tirelessly every day to deliver impactful programs and services to local communities across the country.



Prior to APDA, Leslie has held leadership positions with several major non-profit health organizations including the National Multiple Sclerosis Society, the Alzheimer's Association and the Leukemia & Lymphoma Society.

Leslie is a passionate advocate for the Parkinson's community and looks forward to the day when the mysteries of Parkinson's disease have been solved – once and for all.

Binith Cheeran is the Director of Medical Affairs for Neuromodulation at Abbott. In this capacity, he provides input on research and development, clinical study strategy, design, and execution, regulatory and health policy matters, and he acts as a liaison with physicians and payers. Dr. Cheeran joined Abbott in March 2018.

Prior to joining Abbott, he worked at the John Radcliffe Hospital in Oxford as a neurologist on the functional neurosurgery team, optimizing patient assessment pathways and improving outreach to referring physicians. He was an early adopter of Directional DBS technology, and developed the design and algorithms that underpin the Informity™ documentation and decision support tool.

Dr. Cheeran completed his Ph.D. at the University College of London's Institute of Neurology. He has received several awards for his research, including the Movement Disorders Society Young Investigator Prize in 2008 and the Queen Square Prize in Neurology.

Dr. Cheeran lives in Texas with his wife and daughter. He enjoys travel, chocolate and spending time with his family.

Gail Cohen is the Senior Vice President of Corporate Communications at Acorda working closely with cross-functional teams to build and lead a cohesive communications narrative for Acorda – this includes disease state and product communications initiatives in the Parkinson's arena. Gail joined Acorda after a short stint consulting for Novartis where she was the business communications lead for the Gilenya business unit.

Bringing 25 years of experience to this position, Gail has pioneered some of the communication industry's most successful pharmaceutical campaigns and has led numerous award-winning programs. She is a recognized expert in pharmaceutical marketing and issues management. Prior to joining the corporate world, Gail was on the executive leadership teams of multiple full-service marketing communications agencies including W2O, Burson-Marsteller/WPP, Chandler Chicco Companies/Syneos Health and was responsible for driving new business initiatives and organic client growth, global coordination and management of offices and affiliate relationships and creating unique branding platforms.

Gail graduated from the Syracuse University Newhouse School of Communications with a dual degree in advertising and international politics. She is a native New Yorker and lived in NYC her entire adult life until recently when she made a move to the very far west side of New York (aka New Jersey).

Emma Collin has a professional background and extensive experience in the not-for-profit and local government sectors. Prior to joining Parkinson's Victoria as CEO, she held a number of senior management roles including Executive Manager, Carer Representation and Engagement with Carer's Victoria and General Manager, Community Services with Melton City Council.

The focus of Emma's current role is on securing government, philanthropic and community support for people with Parkinson's, including legislative and social policy reform. She leads a dynamic team who provide information, education, advice and peer support services to the Parkinson's community as well as manage fundraising and community awareness raising activities.

Emma is a passionate advocate for vulnerable members of the community. She is committed to ensuring people living with Parkinson's and their families are able to have a representative voice and access to a range of high-quality services that are flexible and responsive to individual needs. Emma holds a Bachelor of Business from RMIT and is currently completing her Executive MBA at RMIT University, Melbourne.

Sharmila Donde is Director – Community Development and Training at the Parkinson's Disease and Movement Disorder Society (PDMDS) India. The focus of her work with the organization has been the development of Innovative strategies to reach the unreached People with Parkinson's living in rural and tribal areas in the country. This involves planning, monitoring and evaluation of support and rehabilitation programs in the community. An important strategy is the identification and training of people from the community to implement the program.

Prior to her work at the PDMDS, Sharmila was working with Not for Profit Organizations in the field of disability for two decades. As Deputy Director-Training at ADAPT (formerly the Spastics Society of India) she has headed an Asia Pacific Course on Community Initiatives in Inclusion and has guided participants on setting up community programs in different countries. She was invited to the House of Lords, London to present her work of training professionals in setting up community outreach programs in Asia Pacific region.

Natasha Fothergill Misbah is a PhD student at Newcastle University in the UK funded by the Economic and Social Research Council. Her research is exploring the lived experiences of people with Parkinson's disease in Kenya, within the context of global health and ageing in sub-Saharan Africa. She carried out 9 months of ethnographic fieldwork in different sites across Kenya in 2018, and 1 month of follow-up work in 2019. She has a Biomedical Sciences undergraduate degree and a masters in Global Health from Newcastle University. During her masters she travelled to the Hai region of Tanzania to carry out research on Parkinson's disease. She has a particular interest in the health of older populations, specifically in sub-Saharan Africa, and has also carried out an Ageing in Africa gerontology short course through Southampton University. She grew up in Kenya until she moved to UK in 2006 and has always been aware of the disparities in healthcare in the region.

Steve Ford joined Parkinson's UK as Chief Executive in 2005 after a career as General Manager and Chief Executive in the NHS. Under his leadership, we've made significant progress towards our vision to find a cure and improve life for everyone affected by Parkinson's.

Steve believes strongly that change is best delivered in partnership. He's bringing together everyone in the Parkinson's community to speed up research, raise standards of care and empower people affected by the condition to take more control of their lives. Putting people living with Parkinson's at the heart of the charity has created passion and urgency. Steve believes that is the key to achieving our ambitious goals.



Joyce Gordon is CEO of Parkinson Canada and Chair and founding member of Neurological Health Charities Canada. Parkinson Canada is the national voice of Canadians living with Parkinson's disease providing education and services to support people with Parkinson's, caregivers, families and health teams. Parkinson Canada advocates with federal, provincial and territorial governments on issues that matter to the Parkinson's community and funds innovative research to search for better treatments and a cure.

Joyce has over thirty years of experience in the not-for-profit, government, hospital, and education sectors. She was successful in securing \$15M from the federal government for the first National Neurological Population Health study in Canada. Working with the Parkinson Canada Board of Directors she facilitated the investment of \$1M in a new transformational initiative, the Canadian Open Parkinson Network, in which \$1M in matching funds was secured from the federal government. This project will pool data from 15 universities to maximize the potential of research that already exists to get improved health outcomes for people with Parkinson's. She has served on many national task forces on health and active living. She lives in Toronto, Ontario with her husband and three sons.

Kosei Hasegawa is the president of Japan Parkinson's Disease Association (JPDA). Mr. Hasegawa graduated from Nihon University in 1960, and after serving as an employee of a local public service and an association, he worked independently as a architecture-related consultant. Based on his experience, it took about 10 years before his wife was officially diagnosed with Parkinson's disease. At that time, he joined the JPDA with his wife in 1993. Since joining the organization, he has helped plan many JPDA events and has served an executive of the JPDA Gifu branch. He has been President of JPDA since 2018. As president of the JPDA, his focus is to manage the organization to improve the medical care and welfare for PwP until the cure is discovered. Until that time, he works to ensure the PwP and families maintain their dignity and a good quality of life.

Malcolm Irving's work has taken him to many exciting places where he suffered with duodenum ulcers when working in Scotland and Europe, caught whooping cough in NZ, and with a degree of inevitability was diagnosed with Parkinson's in August 2009 in Australia. On the 4th of January this year he had DBS surgery.

His wife, Alison, is a special needs teacher, and he has two daughters Jennifer, who lives in the USA, and Joanna who lives and works in Canberra, Australia.

From a career perspective he has worked on the International Space Station, ran the European Commission's Science and technology on-line publication programme, was COO of one of the Financial Times publishing companies, IBM partner on the Federal government smart city, smart grid initiative, CIO for an Energy Retail company, Vice President of Parkinson's NSW, and now works in the area of business analytics.

Paul Jackson-Clark has been the Director of Fundraising at Parkinson's UK since 2009, where he has led growth in voluntary income from £16m (USD\$21m) to over £35m (USD\$45m). Paul has over 20 years' experience in the voluntary sector and has a broad experience in all areas of fundraising.



Sarah Jones is the CEO of Parkinson & Movement Disorder Alliance and has more than 25 years of experience leading non-profits and health care programs. Sarah is an energetic, visionary leader who is continually looking for opportunities to increase impact and solve unmet needs. Her expertise extends to creating dynamic work cultures, systemic transformations, and blending passion for mission with innovative, high-quality business models. Sarah has designed programs and led trainings for local, national and international audiences, including groups in Canada and Botswana. Driven by the belief that life is too short to just show up every day, she strives to create a world that we are excited to live in and be a part of.

John L. Lehr brings to the Parkinson's Foundation more than two decades of nonprofit fundraising and management experience, with a strong focus in the voluntary healthcare and medical research sectors. Before joining the foundation, John served as President of Orr Associates, Inc. (OAI), a consulting firm that serves the nonprofit sector. At OAI, John was responsible for daily operations of the firm, as well as management of leading clients including Georgetown University, MedStar Health and Special Olympics.

Prior to OAI, John served as Chief Executive Officer of Food Allergy Research & Education (FARE), where he merged two legacy organizations into one national organization focused on finding medical solutions for and educating the public on food allergy. Previously, John also served as Chief Executive Officer of CureSearch for Children's Cancer, a national research and advocacy organization. From 2004 to 2009, John directed the Cystic Fibrosis (CF) Foundation's Milestones to a Cure Campaign that raised \$175 million in support of CF drug discovery and development. The CF Foundation's venture philanthropy model and John's role in leading the campaign were highlighted in a series of Harvard Business School Case Studies. Earlier in his career, John spent many years at the Children's Hospital of Philadelphia in various fundraising roles.

David Leventhal is a former dancer with the Mark Morris Dance Group (MMDG). Leventhal is currently the program director and one of the founding teachers of MMDG's Dance for PD® (Parkinson's Disease) program, which was originally conceived by Olie Westheimer. Begun in 2001 as a small monthly class for the Brooklyn Parkinson Group, the program has expanded to include weekly classes throughout New York City, training workshops for teachers in cities around the US and abroad, and a network of affiliated classes in more than 100 cities in 16 countries around the world. With a vision for increasing access to the joys and benefits of dance, he's co-produced three volumes of a successful At Home DVD series for the program and has been instrumental in initiating and designing innovative projects involving live streaming and Moving Through Glass, a dance-based Google Glass App for people with Parkinson's. He has written about dance and Parkinson's for such publications as Dance Gazette and Room 217 and has a chapter about the program in two books: Multimodal Learning in Communities and Schools (Peter Lang) and Creating Dance: A Traveler's Guide (Hampton Press).

Sara Lew holds a B.A. (Hons) degree in Sociology and Anthropology from the University Kebangsaan Malaysia, and M.A. in English as a Second Language (MESL) from the University of Malaya. She is currently the President of the Malaysian Parkinson's Disease Association (MPDA), a national support for people with Parkinson's, their caregivers and family members. She has been with the association for the past 24 years. Sara became involved in Parkinson's work because of her late father who had Parkinson's Disease for 21 years before he passed away in 2011. Her aunt is also living with PD.

She spent the professional career in the Banking/Finance Industry. Subsequently, she taught part-time at the university while still volunteering at the MPDA. In 2013 she began to serve full time at the association.

During her tenure as the President of the MPDA, Sara advocated strongly for Parkinson's to be recognized as a disability by the Government so that all people with Parkinson's are able to get

free medication at the Government hospitals and other social benefits, be such as subsidized transportation costs, disability stickers for free parking in public parking areas, etc. The disability status was finally approved by the Government in 2012.

Sarah Mathieson is Vice-President of Communications and Engagement at Adamas Pharmaceuticals. Sarah has specialized in biopharmaceutical communications for 22 years since gaining her BSc (hon) in Biomedical Science, and has gained expertise across the full spectrum of communications. Her most recent role prior to moving to Adamas in the Bay Area was as CEO of Research Autism, a non-profit organization focused on research and information across all areas of autism. Prior to this she held various global leadership roles at GSK including Global Head of Internal Engagement overseeing strategy, brand, leadership, organizational strategy and engagement; Global Head of Pipeline (R&D) communications with a focus on financial, scientific and crisis communications, and new product approvals; and Senior Director, Corporate Product Communications. During her time at Pfizer UK, Sarah was Head of Product Communications, responsible for over 20 products at all stages of product development, and spent the early years of her career in medical education and communications agencies, leading corporate communications, public relations, advocacy and medical education across a wide range of diseases, including Parkinson's disease, multiple sclerosis and epilepsy.

Alison Miller, MBA is National Strategic Partnership Manager with Us WorldMeds. She has been with US World Meds since 2012. Her focus is on supporting patient advocacy, market research, and collaboration with PD organizations and key opinion leaders. She has thirteen years of experience in the pharmaceutical industry with a prior background in the banking industry.

Claudia Martinez graduated as a primary care physician in her native Colombia. After she moved to Arizona - USA, she completed a graduate certificate in gerontology at Arizona State University. In 2007 she started the Muhammad Ali Parkinson Center's Hispanic Outreach Program, with the support of a grant from the Parkinson's Foundation. Since then, she has developed a comprehensive and culturally sensitive program for Hispanic families living with PD that is currently recognized as the largest in the United States.

In the last 6 years Dr. Martinez has expanded the MAPC Hispanic Outreach overseas by delivering a series of successful PD specific webinars and conferences while developing a strong international network. Her experience in developing programs for the Hispanic PD community helped her win a Parkinson's Foundation Community Grant to develop a Hispanic Outreach Leadership Conference in 2020. With this initiative Claudia aims to train, empower and connect Hispanic leaders in the USA, so they can confidently start their journey in developing much needed services for Hispanics with Parkinson's disease and their families.

Elena Nikonova, MD – Medical Director, US Medical Affairs, Kyowa Kirin. Elena Nikonova, MD is currently leading US Medical Affairs team within CNS franchise at Kyowa Kirin. Prior to Kyowa Kirin, she worked on Eisai's US Medical Affairs Neurology team. Elena has led cutting-edge collaborations with top academia in neurodegenerative and sleep disorders including the study of LRRK2, Sleepless, comparative transcriptomics of human choroid plexus in Alzheimer's disease, frontotemporal dementia and Huntington's disease among others.

She obtained her medical degree from the Russian State Medical University followed by a NIH/NRSA Post-doctoral fellowship at the University of Pennsylvania within Neuroscience and Sleep. She was a recipient of Young Investigator Award from American Academy of Sleep Medicine working on adenosine metabolizing enzymes in ageing and sleep as well as ATP/energy regulation in sleep deprivation.

Elena is passionate about bringing new treatments to patients with Parkinson's disease and dedicates her work to decreasing patients' disease burden in order to allow them to lead fuller lives.

Genko Oyama is an associate professor of the Department of Neurology at Juntendo University Faculty of Medicine. He has been a courtesy Associate professor of the Department of Neurology at the University of Florida.

Dr. Oyama graduated from Saitama Medical University in 2002 and completed his residency in neurology at Juntendo University Hospital and affiliated institutes in 2006 under Professor Yoshikuni Mizuno. He studied neurophysiological analysis of genetic mice model of Parkinson's disease under Professor Nobutaka Hattori, and obtained his PhD degree from Juntendo University Faculty of Medicine in March 2010. He completed his movement disorder fellowship under Professor Michael Okun at the University of Florida, Center for Movement Disorders & Neurorestoration, USA, from 2009 to 2011.

Genko's research interests have been focused on the neuromodulation technology, particularly deep brain stimulation (DBS) for movement disorders and neuromodulation using optogenetic and induced pluripotent stem cells (iPSC). In addition, he is also conducting research projects for information communication technology and telemedicine for movement disorders. He is a chief of DBS team in Juntendo University Hospital, and also involved in exercise program for people with Parkinson, and serving as a secretary Japan Parkinson Congress.

Leilani Pearl guides the communications strategy of the foundation and executes marketing campaigns to increase awareness of Parkinson's disease. Leilani is passionate about global health issues and health care advocacy.

Leilani began her career in non-profit healthcare communications for Planned Parenthood League of Massachusetts, where she partnered with local media to promote women's health initiatives. Prior to that, she spent nearly a decade in education, teaching literature and writing at Boston College and the University of Puerto Rico. She also worked closely with high school students as an English teacher and administrator in Boston, MA.

Leilani holds an M.A. in English from Boston College and a B.A. in English from the University of Vermont. She serves as a volunteer mentor for the Women of Tomorrow Mentor & Scholarship Program, a nonprofit organization in Miami, FL, that works with at-risk young women in high school.

Jo-Anne Reeves is Chief Executive Officer at Parkinson's New South Wales in Australia. She has thirty years of experience in the for-purpose and related sectors. She worked in a variety of senior roles including communications, fundraising, bequest management and corporate relations before being appointed CEO of Parkinson's NSW in early 2017.

Prior to taking up her current role, Jo-Anne was General Manager of Fundraising and Marketing for Disability Services Australia. She has a wealth of experience in the for-purpose sector and has worked with organisations such as the University of NSW Foundation, The Children's Hospital Westmead Fund, and the NSW Breast Cancer Institute.

In her role as CEO of Parkinson's NSW, Jo-Anne is responsible for diversifying sources of funding to enable the expansion of services for people living with Parkinson's. She is strongly focused on advocating and seeking funding for the placement of more community-based Parkinson Neurological Nurses in Local Health Districts across NSW.

Other key projects she is directing include the development of stronger governance and more open communication with 77 Support Groups across the state, forging industry partnerships to deliver more cost-effective services such as Parkinson's-specific exercise classes, and achieving registration as an Authorised Service Provider with both the National Disability Insurance Scheme and My Aged Care.



Debbie Shapiro is the founder and executive director of the Tikvah for Parkinson Wellness Center. The Center serves the over 10,000 people with Parkinson in greater Jerusalem through daily morning or afternoon wellness programs, support groups for family members, and monthly lectures for the community.

Diane Stephenson is a neuroscientist by training with 30 years combined experience in academic neuroscience and drug discovery. Dr. Stephenson is passionate about translational science and is dedicated to the discovery of therapies to treat diseases of the nervous system. In her academic career, she focused her research on Amyotrophic Lateral Sclerosis and Alzheimer's disease. While in industry she focused on drug discovery for Alzheimer's disease, stroke, and Parkinson's disease. Diane has over 55 scientific publications and six patents in the neuroscience area. Her specific areas of technical expertise include neuroimaging, neuropathology and animal model characterization. As an ambassador for public-private partnerships, she has initiated numerous external academic collaborations including worldwide alliances. Diane received her undergraduate degree in Biochemistry at University of California, Santa Barbara and her PhD in Medical Neurobiology from Indiana University. In her current role, Diane leads multidisciplinary teams comprised of academic experts, industry scientists, patient advocacy groups and regulatory experts collectively aimed at accelerating treatments for patients with neurodegenerative diseases.

Munal Subedi is an assistant professor of Microbiology. He was diagnosed with Young Onset Parkinson's six years ago at the age of 38. He is a founding member and President of the Nepalese Parkinson Disease Association. He is a motivational speaker in Nepal and beyond. He encourages NPDA members to not focus on the future because it's so unpredictable but to live for each day. In his present condition, the effect of the medicine wears off in 2 hours and suffers acute stiffness in his right hand and uncontrollable tremor in the right leg which makes daily life very difficult, but he pulls himself up myself mentally and rides a scooter to teach at the University, not letting his PD derail him.

Ronnie Todaro has served the Parkinson's Foundation for more than a decade. As Chief Operating Officer, she ensures that the foundation's resources meet the needs and priorities of people living with Parkinson's through organizational strategy, execution and day-to-day operations. She is a recognized leader in patient engagement at the foundation and in the community. As an advocate amongst industry, government, academia and nonprofits, she has worked to change the understanding of people with Parkinson's, seeing that their insights are recognized and drive the foundation's work in improving treatments and finding a cure.

Previously, Ronnie held several leadership positions in the public health field, including her time with Planned Parenthood. She was formerly the Chair of the Patient Leadership Council, which was part of the Executive Committee for the Clinical Trials Transformation Initiative (CTTI). She has been an invited speaker at national and international conferences hosted by the NIH, U.S. Food and Drug Administration, Society for Clinical Trials and the World Parkinson Congress. Ronnie currently serves as a member of the Advisory Panel on Patient Engagement for the Patient-Centered Outcomes Research Institute (PCORI) and on the Advisory Committee of North America for the Drug Information Association and the Institutional Review Board at the North Shore-Long Island Jewish Health System. Ronnie earned her M.A. in Public Health in Planning and Administration from the University of Michigan and her B.A. in Public Policy at Cornell University.

ATTENDEES

WPC Leadership Forum

Name	Organization	Website / Email
Binithe Cheeran	Abbott	www.abbott.com
Mimi Quinn	Abbott	www.abbott.com
Gail Cohen	Acorda Therapeutics	www.acorda.com
Jean Hubble	Adamas	www.adamaspharma.com
Sarah Mathieson	Adamas	www.adamaspharma.com
Natasha Fothergill-Misbah	Africa Parkinson's Disease Foundation	www.africaparkinsons.org
Leslie Chambers	American Parkinson Disease Association	www.apdaparkinson.org
Robin Kornhaber*	American Parkinson Disease Association	www.apdaparkinson.org
Dan Raican	Asociata AntiParkinson	
Sue Williams	Australasian Neuroscience Nurses Association Movement Disorder Chapter	www.anna.asn.au
Jesse Cedarbaum	Biogen	www.biogen.com
Kotaro Funato	Biogen	www.biogen.com
Amy Ng	Community Transcultural Support Services	www.communitytranscultural-supportservices.org
Diane Stephenson	Critical Path Institute	www.c-path.org
Helen Matthews	Cure Parkinson's Trust	www.cureparkinsons.org.uk
Elisabeth Ildal	Cure4Parkinson	www.cure4parkinson.com
David Leventhal	Dance for PD	www.danceforparkinsons.org
Polly Dawkins*	Davis Phinney Foundation	www.davisphinneyfoundation.org
Max Coslov	Edmond J. Safra Foundation	www.edmondjsafra.org
Russell Patten	European Parkinson Disease Association	www.epda.eu.com
Kathleen Crist	Houston Area Parkinson Society	www.hapsonline.org
Genko Oyama	Japan Parkinson Congress	
Eiichi Hayashi*	Japan Parkinson Disease Association	www.sites.google.com/site/jpdaorg/home
Kosei Hasegawa	Japan Parkinson Disease Association	www.sites.google.com/site/jpdaorg/home
Elena Nikonova	Kyowa Kirin	www.kyowa-kirin.com
Angela Halpern	LSVT Global	www.lsvtglobal.com
Cynthia Fox	LSVT Global	www.lsvtglobal.com
Sara Lew*	Malaysian Parkinson's Disease Association	www.mpda.org.my
Claudia Martinez*	Muhammad Ali Parkinson Center	www.barrowneuro.org/get-to-know-barrow/centers-programs/muhammad-ali-parkinson-center
Munal Subedi	Nepalese Parkinson Disease Association	www.nepda.com.np
Thyra Kirknes	Norwegian Parkinson's Disease Association	www.parkinson.no
Magne Fredricksen*	Norwegian Parkinson's Disease Association	www.parkinson.no

Name	Organization	Website / Email
Margarita Makoutonina	ParkiLife Australia	www.parklifegroup.com.au
Sarah Jones	Parkinson and Movement Disorder Alliance	www.pmdalliance.org
Andrea Merriam	Parkinson and Movement Disorder Alliance	www.pmdalliance.org
Chun-Hwei Tai	Parkinson Alliance of Taiwan	www.pdcare.org.tw
Joyce Gordon	Parkinson Canada	www.parkinson.ca
John Lehr	Parkinson's Foundation	www.parkinson.org
Ronnie Todaro*	Parkinson's Foundation	www.parkinson.org
Leilani Pearl	Parkinson's Foundation	www.parkinson.org
Jean Blake	Parkinson Society BC	www.parkinson.bc.ca
Michael Schwarzschild	Parkinson Study Group	www.parkinson-study-group.org
Jennifer Cody	Parkinson Voice Project	www.parkinsonvoiceproject.org
Paula Gilmore	Parkinson's Association of Ireland	www.parkinsons.ie
Malcolm Irving*	Parkinson's New South Wales	www.parkinsonsnsw.org.au
Jo-Anne Reeves	Parkinson's New South Wales	www.parkinsonsnsw.org.au
Andy Butler	Parkinson's People	UK
Steve Ford*	Parkinson's UK	www.parkinsons.org.uk
Paul Jackson Clark	Parkinson's UK	www.parkinsons.org.uk
Celia Robinson	Parkinson's Victoria	www.parkinsons-vic.org.au
Emma Collin*	Parkinson's Victoria	www.parkinsons-vic.org.au
Gerald Ganglbauer	Parkinsonline	www.pon.or.at
Maria Barretto*	Parkinson's Disease and Movement Disorder Society	www.parkinsonssocietyindia.com
Sharmila Donde	Parkinson's Disease and Movement Disorder Society	www.parkinsonssocietyindia.com
Joyce Johnson	Rock Steady Boxing, Inc.	www.rocksteadyboxing.org
Gaynor Edwards	Spotlight YOPD	www.spotlightyopd.org
Eleonor Hogstrom	The Swedish Parkinson Association	www.parkinsonforbundet.se
Debbie Shapiro	Tikvah for Parkinson	www.tikvah4parkinson.org
Tim Hague	U Turn Parkinson's	www.uturnparkinsons.org
Fumiko Moriya	U60 Challenged Group	Japan
Akihito Tokoyama	U60 Challenged Group	Japan
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ABOUT THE WPC

The World Parkinson Coalition[®] provides the only international forum on Parkinson's disease that invites all stakeholders to learn about the latest scientific discoveries, medical practices, and care initiatives that improve the lives of people living with Parkinson's disease. By bringing the full Parkinson's community together, including people living with Parkinson's, we hope to expedite the discovery of new treatments for this devastating disease until a cure is found.

www.worldpdcoalition.org