



14 April 2022

## **IAPRD Annual Report for 2021**

The International Association of Parkinsonism & Related Disorders (IAPRD) is an independent, international, not-for-profit, professional association of clinicians, scientists, and other healthcare professionals who are interested in movement disorders, including Parkinson's disease, other parkinsonian disorders, hyper- and hypokinetic movement disorders, and any disorder affecting muscle tone and motor control. This report reflects the activities of 2021.

### **Board and Administration**

The current board members are Dr. Daniel Truong (President, 2015-2023), Prof. Dr. Erik Wolters (Past President 2015-2023), Prof. Dr. Alberto Albanese (President-Elect 2021-2023), Prof. Dr. Elena Moro (Treasurer, 2021-2025), Prof. Dr. Jaroslaw Slawek (Secretary, 2021-2025), Asst. Prof. Dr. Andreas Puschmann (Councilor 2018-2022), and Dr. Mark Lew (Councilor 2019-2023). Dr. Mary Ann Chapman continues as the Executive Director to run the administrative function of the association. Mr. De Tran is the Communications Editor and Mr. Peter Luu is the Webmaster. The IAPRD officers and new committee members are listed on our web page at <https://www.iaprd.info/>.

### **IAPRD Move from the Netherlands to the United States**

Following the resignation of Prof. Dr. Erik Wolters from the financial administrative role held with the IAPRD based in the Netherlands, the membership voted to close that organization and donate the funds and other assets to the IAPRD in the United States. The Netherlands organization was closed in accordance with Dutch law and with the assistance of VHN Notarissen, a notary organization based in the Netherlands.

The IAPRD-NA in the United States officially changed its name to the International Association of Parkinsonism and Related Disorders (IAPRD), dropping the NA designation. The IAPRD Board voted to accept the donations from the IAPRD in the Netherlands, which included monetary and non-monetary components, including the international congress, journals, working groups, webinars, and website content. The IAPRD Board also voted to modify the organization's bylaws to mirror those of the IAPRD (Netherlands), updated to conform to United States law. The bylaws are currently being updated by Eliot Krieger at SKT Law (<https://skt.law/>).

## **Annual Financial Report**

The balance in the IAPRD account as of 31 December 2021 was \$1,058,584.15. The IAPRD received a donation of \$993,039.48 from the IAPRD Netherlands as described above and \$62,000.00 from private donors. Total expenses were \$20,488.35, primarily for administrative costs (personnel, insurance). The annual financial report is available on the IAPRD website.

## **IAPRD Annual Congress**

The XXVI Congress on Parkinson's Disease and Related Disorders (IAPRD 2021) was held from 1-4 May 2021 as an all-virtual meeting and was organized by the IAPRD in the Netherlands. The meeting included 25 scientific sessions, 100 chairs and speakers, and 1,335 registrants from 77 countries. During the congress, the clicks per session were 140-1328 and after the congress on the post-congress platform, the clicks per session were 60-230. Income from sponsors was 211.600 Euros. After all costs were paid, the net surplus of the meeting was 12.890,58 Euros. Outside of these costs, the IAPRD gave a donation of 10.000 Euros to Stichting Symbulon, an African charity promoting the arts, in lieu of a payment to Andre Rieu for his participation in the opening ceremony.

The XXVII Congress on Parkinson's Disease and Related Disorders (IAPRD 2022) is scheduled to take place in Prague, Czech Republic. Congress leaders are as follows: Drs. Andreas Puschmann (Chair of the Scientific Program Executive Committee; SPEC), Joohi Jimenez-Shahed (Co-Chair, SPEC), and Co-Chairs of the Regional Organizing Committee Jan Roth, Irena Rektorova, Maja Trošt, and Elena Moro.

## **IAPRD Journals**

The IAPRD sponsors the journal *Parkinsonism & Related Disorders*, which publishes high-impact clinical, translational and basic science articles in the field. The Co-Editors-in-Chief are Drs. Hubert Fernandez and Vincenzo Bonifati, and the Associate Editors are Drs. Per Borghammer, Yaroslau Compta, Deborah Hall, Beom Seok Jeon, Wassilios Meissner, Zoltan Mari, and Andreas Puschmann; Section Editors (for Movement Disorder Rounds) are Drs. Roongroj Bhidayasiri and Tiago Mestre; Biostatistical Editor is Dr. Michael Heckman, and Social Media Editor is Dr. Thien Thien Lim. PRD's social media presence includes Facebook (<https://www.facebook.com/Parkinsonism-Related-Disorders-431110077692593/>), with 2226 followers, and Twitter (<https://twitter.com/ParkinsonismD>) with 1142 followers. Included in each edition are: In the Spotlight papers with accompanying editorial, Review articles, Point of View papers, Movement Disorder Rounds with expert commentary, Short communications and Correspondences. The IAPRD provides the journal, free of charge, to full members and associate members who request it. The journal impact factor is 4.891.

The IAPRD also sponsors *Clinical Parkinsonism & Related Disorders*, an open access journal focusing on clinical practice and education-related articles. Co-Editors-in-Chief are Drs. Huifang Shang and Daniel Truong; Associate Editors are Drs. Karen Frei, Fernando Luis Pagan, and Eng King Tan. Editorial Board members are Drs. Roongroj Bhidayasiri, Devin K. Binder, Shengdi Chen, Shilpa Chitnis, Jahirul Hoque Chowdhury, Sun Ju Chung, Cynthia L. Comella, Stanley Fahn, Karen Frei, Joseph Friedman, Shinsuke Fujioka, Robert Hauser, Erle Lim Chuen Hian, Joseph

Jankovic, Takuya Konno, Hrishikesh Kumar, Wei-Dong Le, Mark Ledoux, Mark Lew, Chin-Hsien Lin, Gerald Maguire, Davide Martino, Raja Mehanna, James Morely, Elena Moro, Thomas Müller, Rajesh Pahwa, Pramod Pal, Sanjay Pandey, Zhong Pei, Kumar Prakash, Andreas Puschmann, Raymond Rosales, Jan Roth, Marie-Helene Saint-Hilaire, Susanne A. Schneider, Diego Torres-Russotto, Tai Ngoc Tran, Maja Trošt, and Vincent Yun-Cheng Wu. The journal is now indexed in PubMed, Embase, Google Scholar, and Directory of Open Access Journals.

### **IAPRD Newsletters**

The IAPRD issued 3 newsletters in 2021, all of which are available on the IAPRD website: <https://www.iaprd.info/newsletter.html>. The newsletters update members and associate members on organizational information and contain features of interest to the broader movement disorder community. The newsletter Managing Editor is De Tran and the Newsletter Editorial Board members are Drs. Gencer Genc, Valentina Leta, Gertrúd Tamás, Emilia Mabel Gatto, Ryan Walsh, Hubert Fernandez, Mark Lew, Rukmini Mridula, Susanne Schneider, Diego R. Torres-Russotto, and Maja Trošt.

### **Social Media**

IAPRD social media accounts in 2021 were Twitter (1140 followers; <https://twitter.com/PRDAssociation>), and LinkedIn (348 followers; <https://www.linkedin.com/in/iaprd-secretariat-3101a7166/>). The IAPRD posts every ~5 days on Twitter and LinkedIn announcing our activities, journal articles, and other features of interest. Dr. Luca Marsilli began working with the IAPRD on social media in 2021.

### **IAPRD Website**

Following the closing of IAPRD (Netherlands) and the transfer of assets to IAPRD (in the United States), the IAPRD website was moved to a new domain, [www.iaprd.info](http://www.iaprd.info). This website is maintained by IAPRD Webmaster Mr. Peter Luu. The website contains information/links to IAPRD programs and lists IAPRD Board and committee members.

### **International Compendium of Movement Disorders Book**

The IAPRD is developing a textbook titled *The International Compendium of Movement Disorders*, edited by Erik Wolters and Christian Baumann. This book is the second edition of the IAPRD textbook *Parkinson Disease and Other Movement Disorders*, which was published in 2014. The new edition will be published by Cambridge University Press and will comprise 59 chapters and an accompanying video library. The book will offer written and visual insights into current state of the art knowledge of movement disorders and highlight the related latest accomplishments and discoveries. This book will be offered free of costs to students and colleagues in under-served countries around the world. This has been made possible by individual donations to the IAPRD.

### **Myoclonus Expert Panel Working Group**

IAPRD President Dr. Daniel Truong appointed a Myoclonus Expert Panel Working Group to develop myoclonus guidelines. This panel comprises Drs. John Caviness (Chair), Marina de

Koning-Tijssen (Chair), Daniel Truong, Stanley Fahn, Mark Hallett, Kailash Bhatia, Ashley Pena, Emmanuel Roze, Sterre van der Veen, Christos Ganos, Malco Rossi, Anna Latorre, Steven Frucht, Belen Perez-Duenas, and Roberto Erro. The group will meet during IAPRD 2022 to work on updating the guidelines.

### **Tardive Working Group**

The IAPRD Tardive Working Group consists of neurologists and psychiatrists who are working toward a consensus on nomenclature, developing a revised AIMS scale to assess tardive syndromes, conducting research in tardive syndromes, and promoting/sponsoring awareness and education in tardive syndromes. The members of this group are Drs. Joseph Friedman (co-chair), Christoph Correll (co-chair), Stanley Caroff, John Kane, William Ondo, Karen Frei, Robert Hauser, Richard Trosch, Roongroj Bhidayasiri, Daniel Truong, Jonathan Meyer, Leslie Citrome, Joseph McEvoy, Alicia Burris, and Davide Martino.

### **Integrated Care Program for Parkinson Disease**

In 2020, the IAPRD began planning an initiative titled Integrated Care Program for Parkinson Disease. The program is envisioned as a series of video lectures to be placed online in conjunction with one or more journal supplements. Other materials are currently under discussion. The leadership team for this program is Dr. Oksana Suchowersky (Chair), along with Drs. Peter LeWitt, Robert Hauser, and Alberto Albanese. Work on this program will continue in 2022.

### **Donald Calne – IAPRD Scholarship Fund**

The Donald Calne – IAPRD Scholarship Fund was founded to provide support for deserving trainees in movement disorders and to honor Dr. Donald Calne. This fund is overseen by Drs. Ryan Uitti (Chair) and Pramod Pal. The IAPRD will begin fundraising for this scholarship in 2022.

Respectfully submitted,



Jarosław Sławek, MD, PhD

Secretary, International Association of Parkinsonism & Related Disorders