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IPNA ANNUAL REPORT 20 20



IPNA Mission

Our mission is to lead the global efforts to successfully address the care for all children with kidney disease through advocacy, education, and training.



IPNA Vision

Optimal care for all children
with kidney disease.



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IPNA by the Numbers

1847

Programs adjusted to meet COVID-19 requirements while focused on goal to care for ALL children with kidney disease

Members from 116 countries representing every continent

9

physicians completed their fellowships
16 initiated fellowship training

First

IPNA Webinar on Best Clinical Practice

8

in-person IPNA Teaching Courses

27

doctors & nurses participated in the *Saving Young Lives* course in South Africa

300

children were screened for kidney disease in Guatemala as part of a joint project of IPNA, Fundanier and Bridge of Life

New

organized IPNA Foundation to focus on philanthropic support for programs in low resource countries

13

IPNA guidelines dedicated to the diagnosis and treatment of Steroid-Resistant Nephrotic Syndrome in children published in 13 languages

COVID-19

pandemic workgroup developed a resource to facilitate knowledge sharing pertaining to the diagnosis and management of COVID-19 in children with kidney disease

Message from IPNA President



“This virus has also taught us that we must be prepared with alternative ways to continue our programs because kidney disease does not pause during a pandemic.”

Dear Members, Friends, Supporters and Collaborators,

2020 began with several promising new initiatives planned. Then March arrived and all our lives changed dramatically with the emergence of COVID-19. The pandemic impacted our member physicians seeing patients and altered much of our scheduled programming. COVID-19 does not respect borders and has had a devastating impact on the most vulnerable people in countries that have weak healthcare systems and are less prepared to combat the disease. Risk factors were identified in children with kidney disease and physicians stepped up and developed protocols for treating patients. IPNA committee chairs were called upon to develop innovative alternatives to in-person teaching and training that is so vital to clinicians in developing countries. Most importantly, committed physicians and staff are making sure all children receive excellent care whether visiting the clinic for dialysis or participating on a virtual visit. Safety of our patients and their families, physicians and nurses and all healthcare workers is our primary focus.

All over the world adults are being vaccinated and studies are ongoing to determine which vaccines are safe and effective for children. Several countries are on the way back to a new normal and others have limited vaccine supply. Much remains to be done. **This virus has also taught us that we must be prepared with alternative ways to continue our programs because kidney disease does not pause during a pandemic.**

**“We are making
an impact, yet
there is so much
more to be done.”**

To help reach a wider constituency with information pertaining to the most recent activities and achievements of IPNA, we prepared this 2020 Annual Report with robust content about our organization, namely what we do and how it affects children with kidney disease. Most noteworthy is the fact that IPNA's accomplishments are the direct result of membership interacting and volunteering to help make the lives of children with kidney disease better, often through teaching and training of medical professionals in low resource areas. We are making an impact, yet there is so much more to be done.

Our leadership team is dedicated to working collaboratively and I am very proud of the effort put forth by our council and volunteers who have worked together through a challenging year. I am so thankful to my colleagues for their commitment to IPNA and the children we serve. We are reminded daily of their collective resilience, generosity, and kindness. We know this is a difficult time for many people, but what is certain is that medical staff on the front lines around the world need our support. Thank you to our members, sponsors, donors, and volunteers for all you do to care for children with kidney disease and their families.

With much gratitude,



Professor Kim Yap
President

About IPNA



IPNA facilitates the exchange of knowledge and expertise without barriers, does not discriminate and is committed to international understanding.

The International Pediatric Nephrology Association (IPNA) is a nonprofit charitable organization comprised of pediatric nephrologists and allied professionals representing 116 countries around the world. Together, we work to disseminate knowledge about kidney disease in children in the areas where care is needed most. We believe that all children deserve to be healthy and receive optimal treatment and care for kidney disease regardless of their economic position or political choice. IPNA facilitates the exchange of knowledge and expertise without barriers, does not discriminate and is committed to international understanding.

IPNA consists of 7 regional societies:

AfPNA – African Paediatric
Nephrology Association

ASPN – American Society
of Pediatric Nephrology

AsPNA – Asian Pediatric
Nephrology Association

ALANEPE – Asociación Latinoamericana
de Nefrología Pediátrica

ANZPNA – Australian and New Zealand
Paediatric Nephrology Association

ESPN – European Society
for Pediatric Nephrology

JSPN – Japanese Society
for Pediatric Nephrology

IPNA Councilors

The Councilors are responsible for managing the affairs of the Association following the constitution. The executive committee serves as the board of directors and the regional societies from the seven continents are each represented by their secretary.

President

Hui Kim Yap, MD, Singapore

Treasurer

Bradley Warady, MD,
United States

Past President

Pierre Cochat, MD, PhD,
France

President-Elect

Franz Schaefer, MD, PhD,
Germany

Councilors

Hesham Safouh, MD
(AfPNA Secretary), Africa,
Egypt

Michael Somers, MD
(ASPN Secretary),
North America, United States

Arvind Bagga, MD,
(AsPNA Secretary), Asia, India

Melvin Bonilla-Félix, MD,
FAAP (ALANEPE Secretary),
Latin America, Puerto Rico

Fiona Mackie, MB, BS PhD
FRACP (ANZPNA Secretary),
Australia and New Zealand,
Australia

Rezan Topaloglu, MD
(ESPN Secretary), Europe,
Turkey

Kenji Ishikura, MD
(JSPN Secretary), Japan

Francis Lalya, MD, Benin

Bashir Admani, MBChB,
MMED, Kenya

Antwi Sampson, MD, Ghana

Ruth McDonald, MD,
United States

Susan Furth, MD, PhD,
United States

Donald Lee Batisky, MD,
United States

John Mahan, MD,
United States

Mary Leonard, MD, MSCE,
United States

Maury Pinsk, MD, Canada

Pankaj Hari, MD, India

IL-SOO HA, MD, PhD, Korea

Hong Xu, MD, PhD, China

Lim Yam-Ng, MBBS, Malaysia

Khalid Al Hasan, MD,
Saudi Arabia

Francisco Cano, MD, Chile

Nilzete Bresolin, MD, MAST,
Brazil

Florencio McCarthy, MD,
Panama

Jaime Restrepo, MD,
Colombia

Adrian Lungu, MD, Romania

Ali Duzova, MD, Turkey

Giovanni Montini, MD, Italy

Olivia Boyer, MD, PhD, France

Johan Vande Walle, MD,
Belgium

Elena Levtchenko, MD, PhD,
Belgium

Koichi Nakanishi, MD, PhD,
Japan

Ana Teixeira, MD
(Junior Representative)

Portugal

Julian Midgley, BM, BCh
(President of the 19th IPNA
Congress), Canada

Michel Baum, MD
(*Pediatric Nephrology Journal*
Editor), United States

Lesley Rees, MD, FRCPCH
(*Pediatric Nephrology Journal*
Editor), United Kingdom

Strategic Plan

The strategic planning process has helped IPNA redefine the organization's areas of focus and opportunity. It has included an evaluation of the organizations's programs and priorities to ensure they are mission driven. The resulting plan articulates both a vision and path whereby the relevance and value of IPNA can be sustained for the future and is help to guide our activities over the next few years.



“Nearly 500 members engaged in providing input for the Strategic Plan.”

Susan Furth, MD, PhD.
IPNA Strategic Plan Chair

The best plans are dynamic, flexible tools that guide our decision-making process. During implementation, new issues, challenges, and ideas will emerge. We expect to make midcourse adjustments in our plan based on new knowledge and we will share what we learn with our members. IPNA strives to meet current needs and the needs of future generations of pediatric nephrologists and associated partners to help them provide the best possible care to the children and families that need us.

Four Pillars of the IPNA Strategic Plan

Optimal care for all children with kidney disease is IPNA's vision.

1

**Strengthen
IPNA's infrastructure**

Increase
transparency and
improve efficacy

Augment IPNA
operations

Enhance functionality
of IPNA's technology
and resources

2

**Enhance capacity
of providers to care
for children with
kidney disease**

Improve educational
and teaching
programs

Facilitate IPNA
member access
to clinical and
educational
resources

Support local efforts
for establishment and
expansion of clinical
infrastructure

Increase interaction
with related societies

3

**Expand and diversify
funding to support
IPNA initiatives**

Promote
philanthropy, grow
investments, and
optimize business
partnerships
to support
educational activities

4

**Increase
engagement
of the Pediatric
Nephrology
Community**

Broaden involvement
and create
opportunities for
IPNA members
to be engaged
in IPNA activities

Expand the IPNA
community to include
patients/families

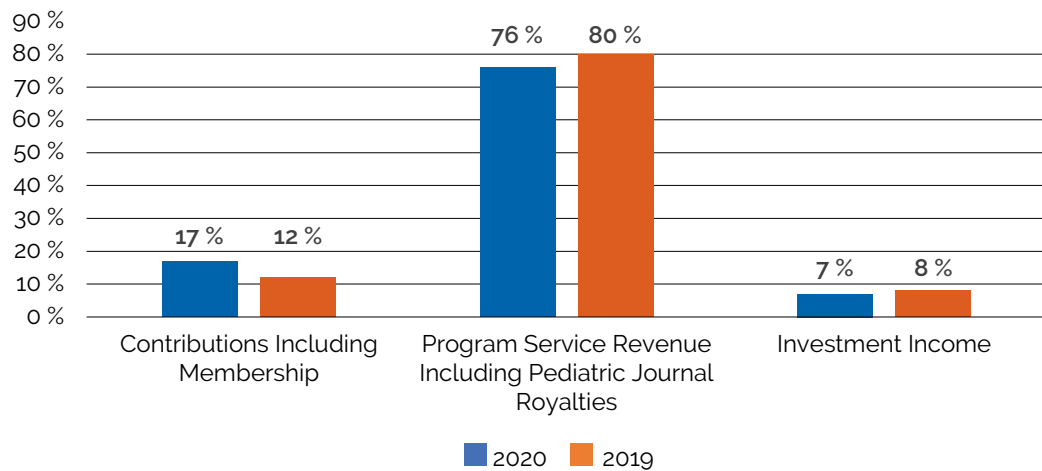
2020 Financial Report

The International Pediatric Nephrology Association is a global nonprofit charitable organization registered in the United States. IPNA files a US 990 Tax Return reporting all income and expenses which is available for public review. Most of the Income is derived from the Pediatric Nephrology Journal royalties and organization membership. We teach and train through fellowships, teaching courses and junior classes. We collaborate with hospitals in developing countries and team up with organizations to best serve the needs of the pediatric kidney disease population. Expenses cover these programs in supporting education & training of pediatric healthcare providers in low resource parts of the world. We have zero expenses for professional training and guidance due to the tremendous in-kind support contributed by IPNA leadership and members donating thousands of professional hours designing and implementing these programs.

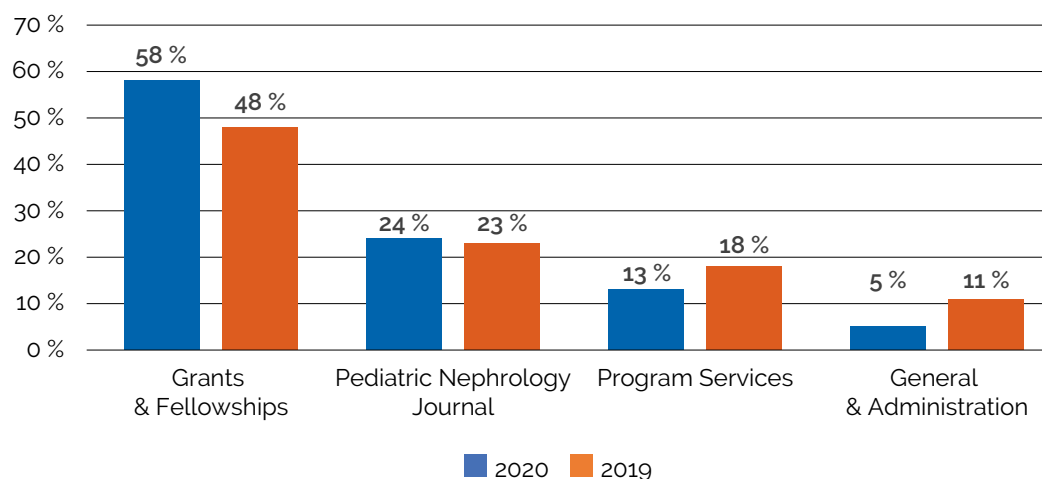
IPNA is committed to nonprofit transparency and has proudly reached the Silver Seal of Transparency Level on GuideStar, a charity watchdog service. The GuideStar database includes roughly 1,5 million recognized charitable organizations in the US, and less than one percent of these organizations have reached this Silver Transparency Level.



INCOME



EXPENSES



"We are committed to effective and efficient management of our resources to fulfill the organization's mission in the most effective and efficient manner possible. We are accountable to IPNA stakeholders, including Council, our membership, funders, and most important, to the community of healthcare providers working hard to achieve the best outcomes for children with kidney disease. As treasurer, I have a fiduciary duty to ensure that IPNA's assets are used in accordance with the members' and donors' intent, and in support of our charitable mission."

Bradley A. Warady, MD
Treasurer

Note: Income & expenses provided by IPNA accounting firm.

IPNA Membership

Members are essential to IPNA's mission as they pass on the knowledge and training they gain to medical professionals all over the world. In 2020, membership grew by 11 % to 1,847 members and a new scholarship program was initiated to support new members from low-resource areas. IPNA is well represented globally with members from 116 different countries.

Member involvement in carrying out IPNA's mission is crucial. We recently published a call for volunteers to join IPNA committees and we received 79 excellent applications which exceeded expectations.

"Growing the membership has been a priority for the IPNA Council. Our member physicians help carry out IPNA's mission and build on the commitment we have made to patients and families dealing with kidney disease."

Arvind Bagga, MD

Dec 2020

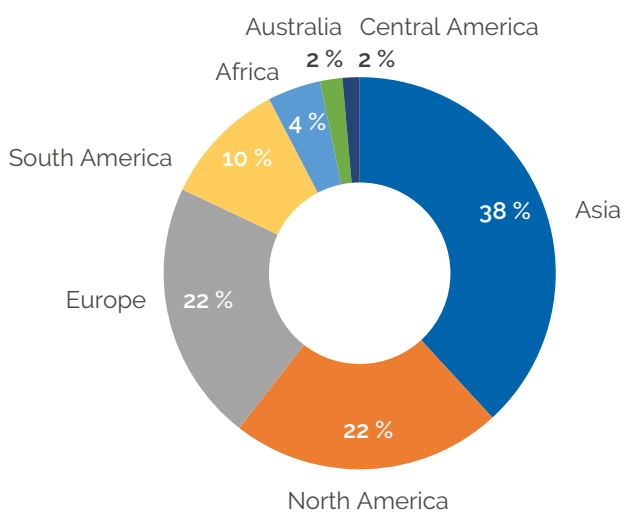
1847
members

Dec 2019

1660
members

Dec 2018

1467
members

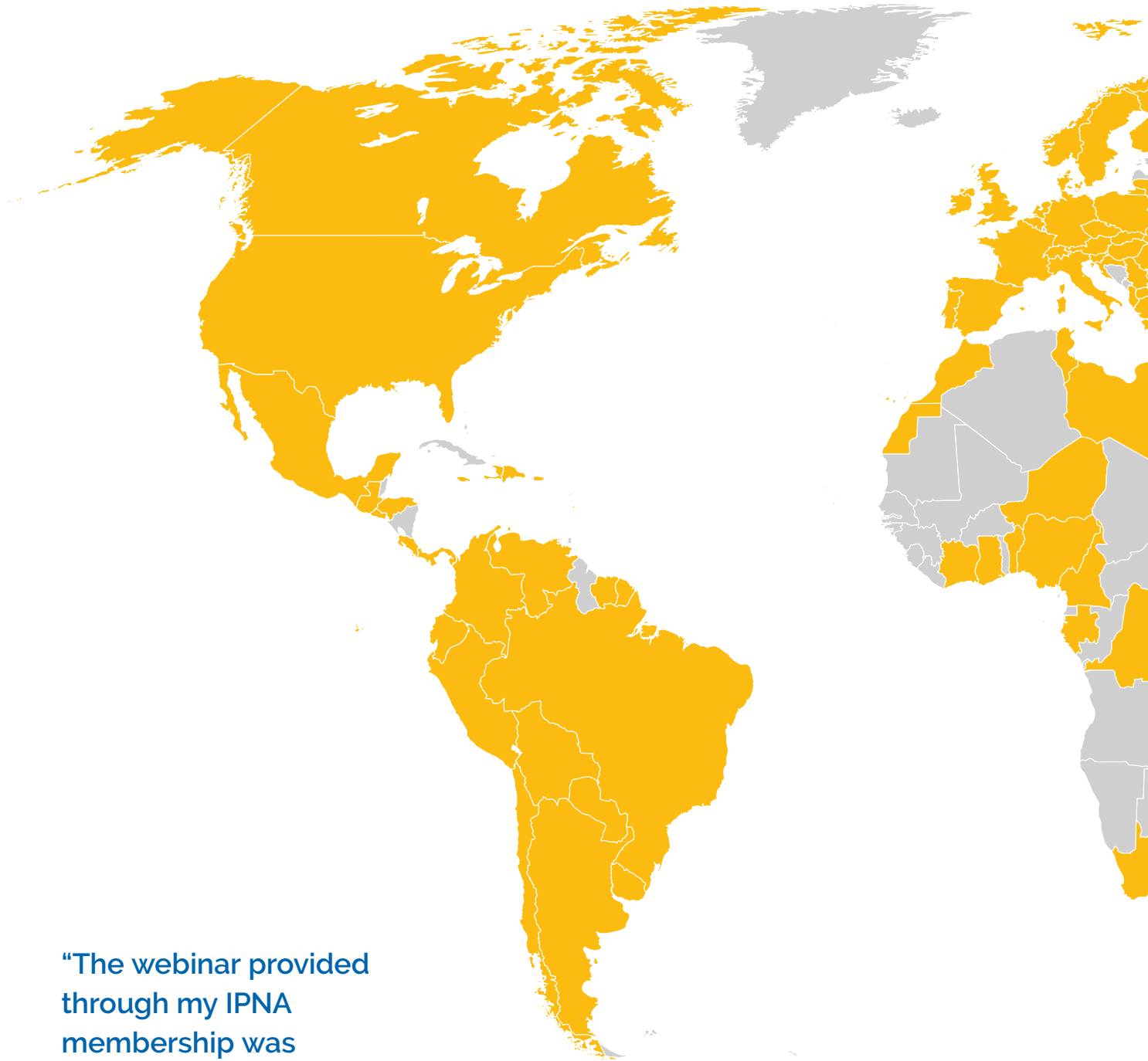


IPNA Membership Representation

"I am gaining good knowledge of the subject matter with my IPNA membership."

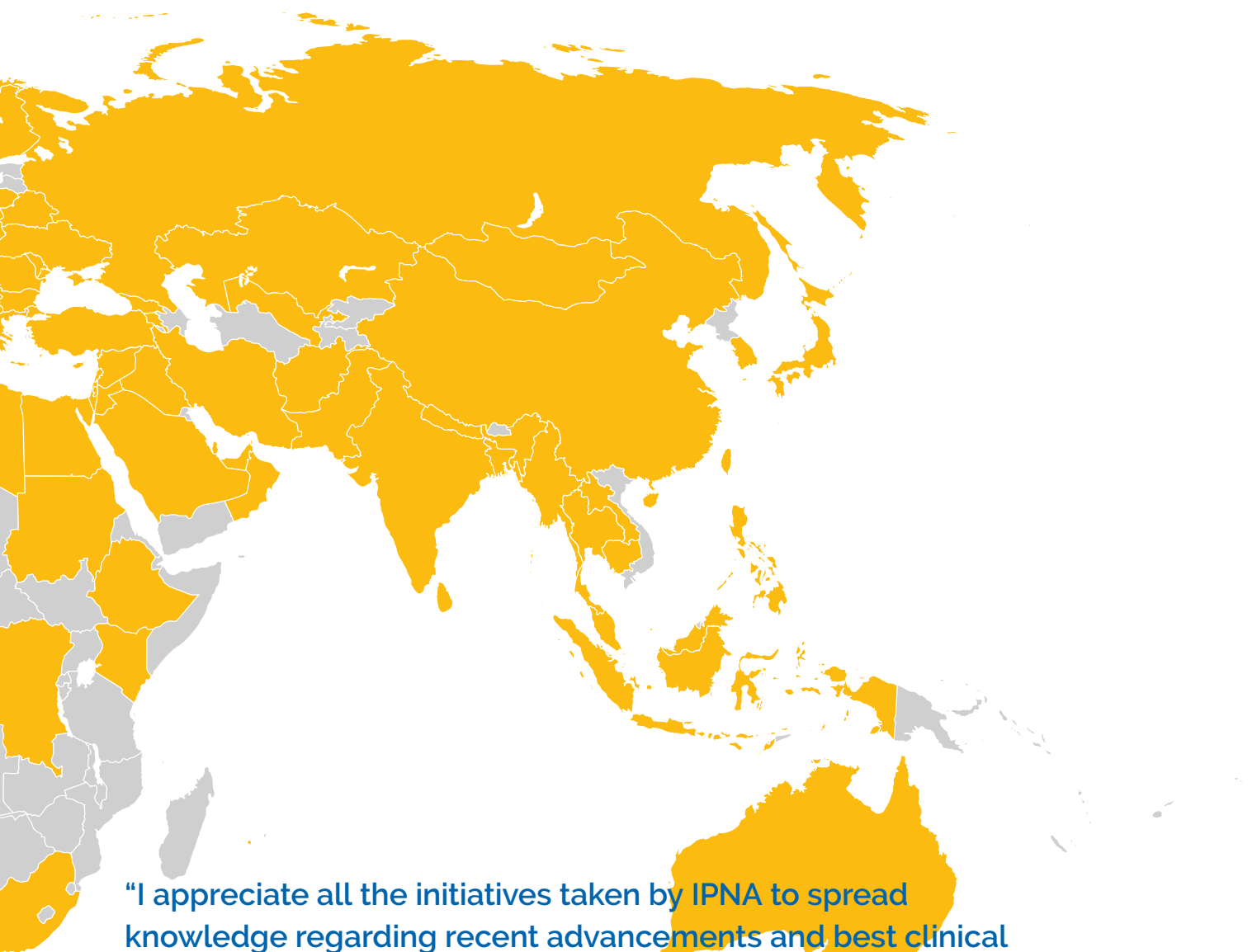
Naureen Akhtar, MD
HOD Pediatric Nephrology
The Children's Hospital
Lahore Pakistan

IPNA Members Around the World



**“The webinar provided
through my IPNA
membership was
excellent.”**

Nisreen Sinada, MD
Inkosi Albert Luthuli
Central Hospital
Durban, South Africa



"I appreciate all the initiatives taken by IPNA to spread knowledge regarding recent advancements and best clinical practices in pediatric nephrology globally, and especially for sharing material from the last IPNA Congress. The Journal, webinars, and access to scientific and clinical detail are of a great help to the pediatric nephrologists from Kazakhstan. IPNA provides the information necessary to stay up-to-date and deliver better management in our daily clinical practices."

Marina Khvan, MD

Nazarbayev University School of Medicine

Astana, Kazakhstan



IPNA Educational Programs



GREAT CARE FOR LITTLE KIDNEYS. EVERYWHERE



Fellowship Program

IPNA established the Fellowship Program to provide pediatricians in underserved regions around the world with training in pediatric nephrology. Fellowships have been offered in 24 countries, with more than 250 completed since 2003. Accomplishments during 2020 included updating the IPNA Fellowship Handbook, refining the application and reporting process and greater committee participation. The Committee is working on better defining the needs of pediatric nephrologists across the world. This information will help IPNA prioritize fellowships in those global regions with the greatest shortage of pediatric nephrology specialists.

“COVID-19 has restricted travel and border closures have affected our program. We continue to monitor the global situation closely in hopes of reopening the application process once COVID-19 is much better controlled and fellowship training is deemed to be safe.”

Francisco Cano, MD
Fellowship Committee Chair

“This training gave me an opportunity to enhance procedural skills in pediatric nephrology and has boosted my confidence. I will treat children who are suffering from kidney disease in Bangladesh who cannot afford the advanced care available in developed countries.”

Azizur Rahman, MD
IPNA fellow, NUH Singapore



9

Fellows completed
training in 2020.

Fellow countries of origin

China, Burkina Faso,
Sudan, Benin, Egypt,
India

“As an IPNA fellow, I benefited from the enthusiastic support from staff at Children’s Hospital of Fudan University. They encouraged academic research and I learned much in the area of clinical diagnosis, treatment and humanistic care. The staff motivated me with their considerate and selfless care of patients and I appreciated the opportunity to learn.”

Panli Liao, MD

IPNA Fellow, Children’s Hospital
of Fudan University, Shanghai China

Professional Education Committee

Teaching Courses, Webinars, IPNA Congress & Junior Master Classes

2020 was about facilitating professional education in challenging times: moving to virtual platforms for Teaching Courses and Junior Master Classes, refining and expanding our Webinar offerings series into regularly scheduled IPNA Clinical webinars and a new novel collaboration with the International Society of Nephrology (ISN) to create the ISN-IPNA Webinar Series.

1

Teaching Courses (TC)

With the necessary shift from in-person courses to virtual options, the subcommittee worked with hosts to facilitate courses tailored to health care professionals in their regions. Courses were taught by highly trained Pediatric Nephrologists in areas of the world where our specialty is scarce. We learned to expand the reach and provide continuity using the virtual platform for presentations as part of enduring educational materials for post course accessibility. Our committee worked with TC organizers to provide funding and, where needed, access to technology. Our short term goal is to support multiple TC in these formats and we look forward to returning to in-person courses in the future. We are committed and will continue to educate professionals' while learning and adjusting to the most effective methods available.

8

IPNA supported Teaching Courses: Cameron, India, Jordan, Nigeria, Russia, Ukraine

1773

attendees



“Teaching Courses are a core educational activity of IPNA with the highest participant reach.”

John Mahan, MD

IPNA Professional Education Committee Chair

IPNA Nephkids
2020 Teaching Course



JUNIOR MASTER CLASSES (JMC)

IPNA and the European Society of Pediatric Nephrology (ESPN) collaborated to provide Junior Master Classes in a virtual format. The 10-hour course, accredited by the European Accreditation Council for Continuing Medical Education, included 143 participants representing 40 nationalities. IPNA is exploring the possibility of conducting Asian and African (French) virtual versions. Virtual course engagement has been positive as IPNA researches additional expansion opportunities.

Attended by

143 > 40 > 30

students
representing

nationalities
with

students completing
the three-year cycle.

3

IPNA WEBINARS

Monthly webinars are devoted to current clinical practice guidelines or topics of interest to membership. In 2020, we conducted 10 IPNA webinars with 1,695 attendees. A new ISN-IPNA webinar series was launched where presentations are made every four months addressing clinical issues which have implication for children and adults.

3

Joint ISN-IPNA Webinars

13

Professors

2485

Participants of IPNA
and IPNA-ISN Webinars

10

Teaching Webinars on Best
Clinical Practice

IN THE SPOTLIGHT:

First joint
ISN-IPNA
Webinar

A new joint endeavor of the ISN and IPNA kicked off on July 1 with a presentation on 'COVID-19 and the Kidney: Interesting differences and similarities between children and adults'. 279 physicians attended the live presentation and many more viewed the recorded session.

4

IPNA CALGARY 2022 CONGRESS

The IPNA Education Committee along with the Calgary Congress organizers are exploring innovative techniques to enhance the educational methods and value of this triannual event. The committee has shared engaging teaching methods for the organizers to adopt.



IPNA Teaching Course
"Dialysis for Acute Kidney Injury
in Resource-limited Settings",
Nigeria 2020



"Kidney disease prevention advocates from the Philippines Northern and Southern Islands converge every year to receive updates on new clinical practices during our IPNA courses. I am truly thankful for IPNA's assistance with our teaching courses and their immediate response to queries and requests for assistance."

Agnes Alarilla Alba, MD
 Philippines

Sister Centers Program

“Puerto Rico has established the basis for supporting the neighboring countries in Central America, as The Foundation for Children with Kidney Diseases or FUNDANIER in Guatemala becomes an ISN Training Center for Pediatric Nephrology in the region.”

Melvin Bonilla-Felix, MD,
FAAP

The program strategy is to link developing pediatric renal units in low resourced regions to experienced pediatric renal units.

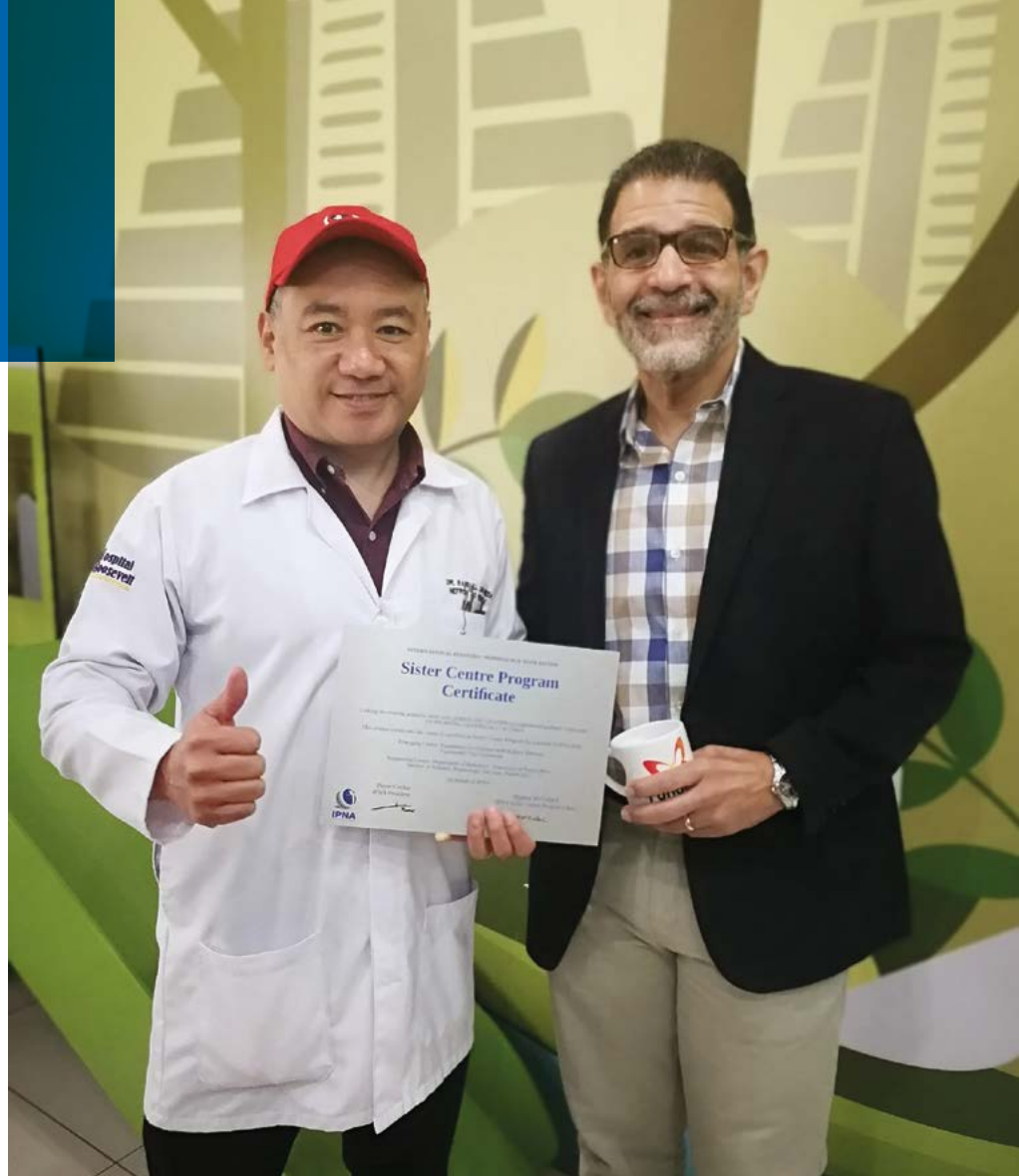
The Sister Center Committee match “mentor centers” with centers from emerging countries with a preference to support previously trained IPNA/ISN fellows as program supervisors. Programs include staff training, upgrading services to children, community education for kidney disease preventative strategies and development of clinical research.

In 2020, Dr. Ijaz’s team from Lahore, Pakistan was supported successfully by Dr. Bagga’s team from the All India Institute of Medical Sciences. A collaboration between IPNA’s inaugural Sister Centers in Guatemala and Puerto Rico was completed successfully, while the collaboration between Nigeria and South Africa is in full swing.

Progress this year includes new initiatives for reporting and developing a waiting list of established Centers seeking emerging Centers to mentor. The demand for Sister Centers has prompted IPNA to plan to award grants to two new Sister Center programs in 2021. Fundanier is and has been the driving force that has facilitated changes in the Guatemalan health system to establish a comprehensive pediatric nephrology program.

Fiona Mackie, BS PHD FRACP

Sister Center Program Chair



Dr. Melvin Bonilla (right)
from the supporting center
in Puerto Rico and Dr. Randall
Lou-Meda from the emerging
center in Guatemala

**“The cooperation
between
our teams has
been wonderful.”**

Shaegan Irusen, MD
Supporting Center,
Charlotte Maxeke
Academic Hospital,
Johannesburg,
South Africa

**“The program has improved
our practice, as our nurses now
do routine urine analysis on all
children on admission, irrespective
of the primary diagnosis.”**

Oluseyi Oniyangi, MD
National Hospital
Abuja, Nigeria

IPNA-ISN Initiatives

Saving Young Lives (SYL)

COVID-19 dramatically affected SYL programs in 2020 with several activities postponed to 2021.

Accomplishments include:

- Acute PD Training Course in Cape Town, South Africa with in-person teams of 27 doctors & nurses from eight African countries.

Acute Kidney Injury (AKI) is a global healthcare challenge with over **13 million people** affected each year, many of whom are children in low resource areas of the world. AKI accounts for **1,7 million** deaths per year with **1,4 million** occurring in developing countries. Identified early, AKI is a preventable and treatable condition. For the past five years, IPNA has participated in the SYL partnership (along with ISN, ISPD, and EuroPD) in developing sustainable peritoneal dialysis (PD) programs to treat children and adults with AKI. We focus on providing training and educational activities in the community to improve awareness and equip local health practitioners with skills to prevent and identify cases needing hospital care. Doctors and nurses receive training across Africa, South Asia and South East Asia (with plans to extend to Latin America) where dialysis training and facilities are rare.

challenge with over

13 million

people affected each year

Mignon McCulloch, MD, MI

Arvind Bagga, MD

William Smoyer, MD, F.A.S.N.

IPNA SYL Representatives





We focus on providing training and educational activities in the community to improve awareness.

Peritoneal Dialysis catheters insertion



Kidney biopsies



Title Preparing Pork Belly Models and Teaching about data collection

Special Projects



World Kidney Day

The World Kidney Day contest to encourage education and screening of children with kidney diseases in developing countries produced two winners who received recognition and a financial award.

1

Dr. Girish Bhatt, Bhopal, India

Title: Educating parents and children together for prevention of kidney diseases

Aims:

- 1)** To raise awareness among nursing students about early preventive strategies for kidney diseases through slogan/painting competition/skits
- 2)** To organize health talks in outpatient departments of hospitals and nearby schools
- 3)** To screen for blood pressure in school children
- 4)** To organize talent shows for children with kidney disease



2

Dr. Azmeri Sultana, Dhaka, Bangladesh

Title: South Asian Association for Regional Cooperation (SAARC) Pediatric Acute Kidney Injury Consortium- Prospective study on incidence and risk factors for 'Severe Pediatric AKI' – Achieving 0 by '25

Aims:

- 1)** To develop a research agenda for ascertaining the epidemiologic characteristics of severe AKI across SAARC nations
- 2)** To establish a multinational prospective AKI database and determine the specific local / regional risk factors and associated outcomes amongst SAARC nations

Guatemala Clinic

IPNA Teams with Bridge of Life
International to Provide Education
and Screening

of 300 Children

in a Guatemala Community
with High CKD prevalence



IPNA partnered with the Bridge of Life (BOL) organization to screen over 300 children at risk for chronic kidney disease (CKD) on March 8–15, 2020 in the La Democracia municipality of Guatemala. Organized locally by IPNA Sister Center, FUNDANIER, the program focused on prevention education for children. Nurses, dietitians and an IPNA volunteer pediatric nephrologist trained local community health workers and doctors about chronic kidney disease prevention.

Thank you for securing one of the best physicians I have ever worked with. Dr. Melvin Bonilla was humble, heartfelt, knowledgeable, and kind. He offered amazing trainings to dozens of residents! He also offered 100s of youth medical consultations, took considerable time with every person he treated, and truly educated about the progression of CKD. Not to mention, he fit perfectly into our group. We all just adored him! I am confident that this was the beginning of a meaningful partnership between IPNA and BOL. We look forward to our continued work with Melvin and other IPNA representatives.

Thank you again.

Katie Chandler

Program Director
Bridge of Life



Best Practices and Standards

Priorities for IPNA guidelines and recommendations for standards for specific care in children are set by this committee. We employ a consensus approach using state of the art evidence-based medicine methodology in the development of Clinical Practice Recommendations (CPR).

The challenge is that many diseases pediatric nephrologists encounter are rare, they require optimal management, but there are a limited number of randomized clinical trials upon which to base treatment recommendations.

Recommendations from the International Pediatric Nephrology Association for the Diagnosis and Management of Children with Steroid-Resistant Nephrotic Syndrome (SRNS)



Patient material created with support from Nephcure Kidney International



IPNA International Pediatric Nephrology Association
GREAT CARE FOR LITTLE KIDNEYS. EVERYWHERE

Visit IPNA: www.theipna.org
Freely accessible at the IPNA website: www.theipna.org/resources/guidelines

1 Diagnosis



Steroid-resistant nephrotic syndrome (SRNS) is the persistence of protein in the urine after 4 weeks of treatment with prednisone/prednisolone. It can lead to decreased kidney function and/or kidney failure.



Genetic testing and a kidney biopsy should be considered in all children with SRNS without a clearly identified cause.



Genetic causes are identified in up to 1/3 of children. If a genetic cause is identified, medications that act on the immune system are not effective and should be discontinued.

2 Treatment



Use of medications that decrease the amount of protein in the urine and protect the kidneys are recommended once the diagnosis of SRNS is confirmed.



Once the diagnosis of SRNS is confirmed, treatment with cyclosporine or tacrolimus (or alternatives) for at least 6 months, should be started. If there is no response after 6 months, they should be discontinued. Medications to manage chronic kidney disease may be used.



Kidney transplant is recommended to all children who reach kidney failure, recognizing that there is a risk of recurrence of nephrotic syndrome in the new kidney. Removal of one or both kidneys in a patient may be needed prior to transplantation.

3 General measures



Encourage physical activity and healthy nutrition. Excessive salt intake should be avoided.



Routine vaccinations including the annual flu shot should be given. Live virus vaccines require caution in children taking immunosuppressive medications. Speak with your doctor before vaccinations.



Different medications may be needed to compensate the loss of proteins in the urine (hormones, vitamins, calcium).

Accomplishments

- Pediatric Nephrology Journal published the first IPNA-CPR; translated in 13 languages and adapted for patient/families; published and available via open access.
- Dissemination of knowledge through webinars, masterclasses, lectures, and publications.
- Organized work groups and consensus meetings for 3 IPNA-CPRs on steroid sensitive nephrotic syndrome, atypical hemolytic syndrome, and IgA nephropathy.
- Organized of virtual IPNA workshop on Evidence-based Clinical Management in Pediatric Nephrology (March 29–31, 2021).
- Surveyed IPNA and regional society's membership to identify the gaps in guidelines for improvement. The results will be published in Pediatric Nephrology in 2021.
- Efforts underway to establish criteria for evaluating clinical research outcomes in pediatric nephrology; part of the new collaborative project to publish consensus definitions of endpoints used in clinical trials.

May 2020

IPNA Clinical Practice Recommendations (IPNA-CPR), addressing important global topics in the field of pediatric nephrology published in *Pediatric Nephrology* Journal.

Olivia Boyer, MD, PhD.

Best Practices & Standards
Committee Chair

Communication

The IPNA Communications Committee supports the IPNA mission through creation, oversight and maintenance of the websites, social media, newsletter, and other communication initiatives.

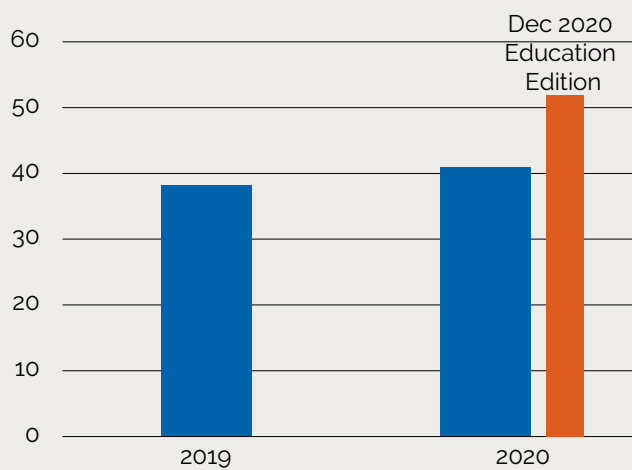
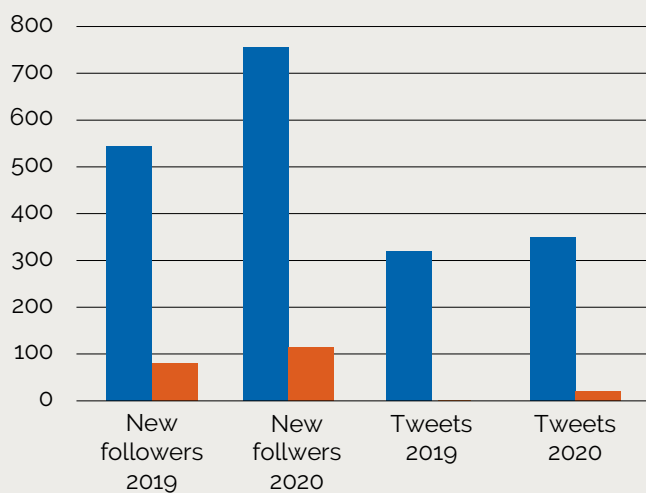
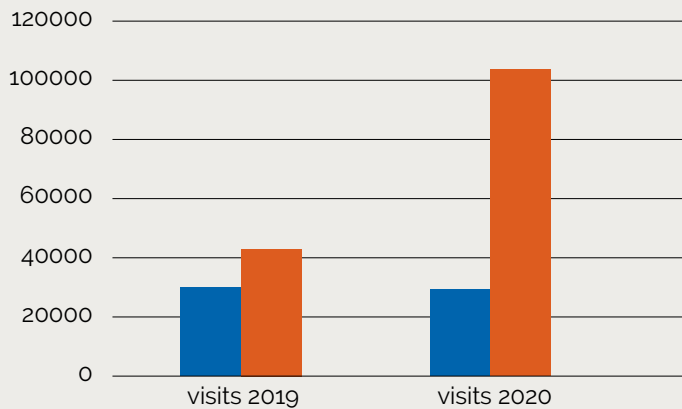
“The Committee has grown to include many amazing volunteers from across the globe, who all have a commitment to learning and developing capacity to support IPNA on electronic platforms. The efforts of the committee have helped create a fresh face of IPNA and engage new members to join in the IPNA mission.”

Maury Pinsk, MD, FRCPC MSc
Communication Committee
Chair

Highlights for 2020

- Welcomed several new members to assist in promotion of IPNA's mission.
- Secured social media training opportunity with experts.
- Analyzed the different audiences and member needs; developed the best way forward for as a key aspect of the IPNA websites upgrade strategy.
- Collaborated with web developer to assure that content align with Strategic Plan.
- Began to implement web host transition and secure financial platform.
- Initiation of live tweeting webinars





*Littlekidneys.org is now IPNAFoundation.org

Registry

Research across the Globe – *International Pediatric Nephrology Association (IPNA) Global Kidney Replacement Therapy Registry*

The registry provides a platform to educate, share information and accelerate the development of effective treatments for pediatric kidney diseases. Trends are identified with an effectively leveraged registry, facilitating the international collaboration among the renal community that is essential to improving global outcomes.

Goal

To include information on pediatric Kidney Replacement Therapy (KRT) from all 189 internationally recognized countries.

The **Global Registry** is the first to collect population-based information.

“Unfortunately, information is scattered and incomplete in many countries and databases are not available for many low-resource countries, leaving a large part of the global pediatric End Stage Kidney Disease population unidentified and health care providers uninformed about the size of the treatment challenges ahead. The IPNA Global KRT will go a long way toward solving this issue.”

Franz Schaefer, MD, PhD.
IPNA Registry Committee Chair

Our mandate

- To provide information on kidney replacement therapy practices and outcomes in the context of socioeconomic conditions
- To provide global pediatric kidney replacement therapy benchmarking
- To empower clinical and translational research using information on disease demographics and comorbidities in children with end-stage kidney disease
- To facilitate interventional trials in children undergoing dialysis and kidney transplantation

Recruitment is progressing with 60 countries having signed Data Sharing Agreements (DSA), including an agreement with the European Society of Pediatric Nephrology and the European Renal Association – European Dialysis and Transplantation Association (ESPN/ERA-EDTA) Registry. Negotiations with the United States Renal Data System (USRDS), Australia and New Zealand Dialysis and Transplant Association (ANZDATA), 10 Asian, 15 South American and 8 African countries are ongoing.

Pediatric Nephrology Journal

Received over 1,000 submissions for the first time.

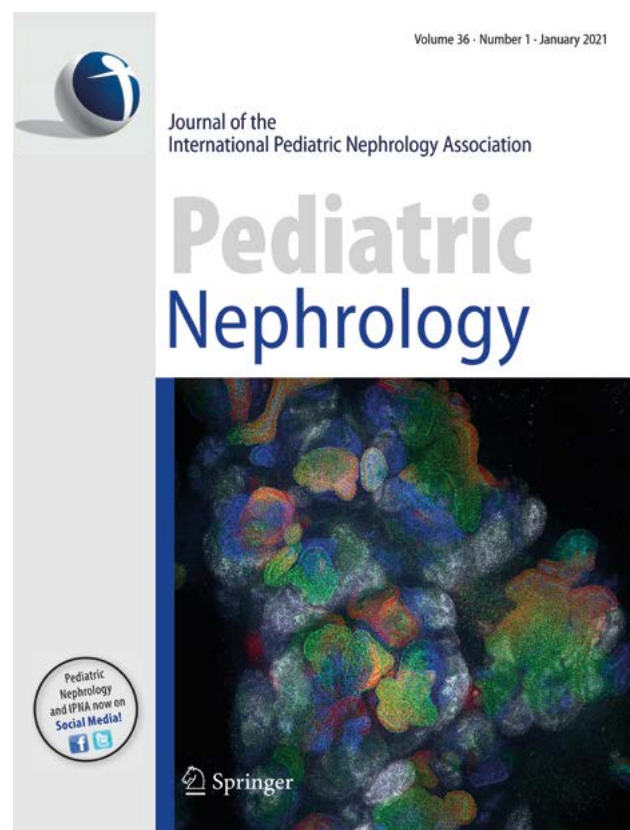
The journal received 1,006 submissions in 2020, a new record, and 50 % more than in prior years. This may reflect the impact of the Coronavirus pandemic as many people, working from home and unable to participate in on-site clinical and laboratory work, had time for writing. Joseph Flynn was selected as the new editor in chief, and he assumed his role toward the end of 2020. The committee will continue to make improvements to the journal, and as always, appreciates and depends on the great contributions from IPNA membership to continually increase the quality of *Pediatric Nephrology*.

"I look forward to finding ways to further enhance an already terrific Journal and seek new ways to serve the IPNA membership."

Joseph Flynn, MD, MS
New Editor of the *Pediatric Nephrology Journal*

	2018	2019	2020
Impact Factor*	2.816	2.676	3.714
Number of Downloads	568,665	619,922	836,677
Submissions	706	705	1,006
Rejection Rate	62 %	65 %	61 %
Published Articles	288	250	391
Print Copies to Society Members	462	437	294

*Impact factor is used to evaluate the relative importance of a journal within its field.





Patient Education

The provision of access by patients and their families all over the world to updated and reliable information on pediatric kidney diseases in a format that is easily understood is an essential element of the educational mission of IPNA. The Patient Education Committee has, in turn, made available information derived from kidney organizations in 32 countries around the globe pertaining to a variety of topics including research, patient treatment, diet, clinical trials and patient support networks. Most important has been the continued progress made in making the information available in a growing list of languages which now includes Arabic, Bangla, Chinese, Danish, Dutch, English, French, German, Gujarat, Hindi, Hungarian, Italian, Korean, Lithuanian, Malayalam, Norwegian, Polish, Portuguese, Spanish, Swedish and Tamil languages. An expanded list of topics, with input from patients and families, in an equally expansive list of languages is being developed by the committee.

Hesham Safouh, MD

Patient Education Committee Chair



IPNA Foundation

The IPNA Foundation was created as the philanthropic arm of the International Pediatric Nephrology Association. IPNA is a non-profit charitable organization which focuses on education and training programs and the Foundation's mandate is growing these important initiatives with support from individual donors, grants, and sponsorships. Operating under the IPNA charitable designation, contributions are included in the IPNA financial report and efforts are transparent to the membership and the public.



Working Together to Save Lives

IPNA's network of 1,800+ pediatric nephrologists and professionals works across 116 countries, operating under the philosophy that all children deserve to be healthy and receive optimal treatment for kidney disease. With improved training programs and long-term follow up, we can dramatically impact the lives of children dealing with kidney disease. Some of the ways IPNA is making a difference in low resource areas include:

- Funding fellowships for pediatricians from developing countries to obtain training in nephrology.
- Teaching courses where pediatricians learn to diagnose and treat kidney issues.
- Forming partnerships among pediatric nephrology units to develop financial and logistical solutions.
- Organizing Junior Working Groups to engage and train young pediatric nephrologists.
- Participating with initiatives, including the Renal Disaster Relief Task Force, Saving Young Lives, and other partnerships with international organizations.

"The measure of our success is in lives saved and the number of children treated by trained physicians."

Isidro Salusky, MD, IPNA President 2007–13

Contact

**IPNA is a nonprofit charitable organization
founded according to United States
Charitable 501c3**

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Pediatric Nephrology
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