IPNA Partners Forum
INTERNATIONAL PEDIATRIC NEPHROLOGY ASSOCIATION

# IPNA Newsletter

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Dear IPNA members and friends,

It is my pleasure to welcome you to the **second edition of the IPNA Partners Forum Newsletter**. Following the launch of this initiative, we are delighted to continue providing a platform that strengthens collaboration and promotes meaningful exchange between IPNA and our valued partners who share our commitment to improving kidney health for children around the world.

In this issue, we are pleased to feature two contributions focusing on the importance of **early recognition and accurate diagnosis in complement-mediated kidney diseases**. Alexion highlights Recognising aHUS in Children: Why Early Diagnosis and Coordinated Care Matter, emphasising the importance of timely recognition and a coordinated approach to care for children with atypical hemolytic uremic syndrome. Sobi explores Time Matters: Early and Accurate Diagnosis of Paediatric C3G and Primary IC-MPGN, highlighting the critical role that prompt and accurate diagnosis can play in the management of these rare complement-mediated kidney diseases.

We are also delighted to share an exciting update on IPNA 2027, with record-breaking engagement from the global paediatric nephrology community. With more than 1,300 abstracts submitted, the Congress is shaping up to be an outstanding opportunity for scientific exchange, collaboration, and shared learning.

We hope this second issue continues to provide valuable insights and encourages dialogue, shared learning, and collaboration across the IPNA community and our partners. Together, we can continue to advance awareness, diagnosis, care, and outcomes for children living with kidney disease.

With sincere appreciation for your continued commitment to IPNA and, above all, to the children at the centre of our mission.

John D Mahan, MD
IPNA Treasurer

John D Mahan

Rukshana Shroff, MD, FRCPCH, PhD
IPNA President

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Alexion

## Recognising aHUS in Children: Why Early Diagnosis and Coordinated Care Matter

Atypical haemolytic uraemic syndrome (aHUS) is a rare, life-threatening thrombotic microangiopathy associated with dysregulation of the complement pathway. It can occur in both children and adults, and is classically characterised by microangiopathic haemolytic anaemia, thrombocytopenia, and acute kidney injury.[1-4] If untreated or recognised too late, aHUS can be associated with substantial morbidity and mortality, including irreversible kidney damage, kidney failure, extra-renal complications, and death.[1,2, 4-6]

The clinical presentation of paediatric aHUS may be heterogeneous. Children may present acutely with kidney injury, hypertension, haematological abnormalities, or multi-organ involvement. Extra-renal manifestations can occur, and early features may overlap with other causes of acute kidney injury or thrombotic microangiopathy, including Shiga toxin–producing Escherichia coli associated HUS and thrombotic thrombocytopenic purpura.[1,3,7,8] This overlap can delay diagnostic consideration, particularly when the full clinical triad is not apparent at initial presentation.[1,2,4]

Early diagnosis relies on clinical suspicion and timely evaluation of thrombotic microangiopathy. Complement and genetic investigations may support disease characterisation, prognosis, and long-term management, but they are not required to establish a clinical diagnosis and should not delay specialist referral or appropriate management when aHUS is suspected.[2]

Given the rarity and complexity of aHUS, coordinated multidisciplinary care is important. Collaboration across paediatric nephrology, haematology, intensive care, laboratory medicine, and genetics can support rapid assessment, exclusion of key differential diagnoses, interpretation of specialised investigations, and timely access to expert input. Structured care pathways may be particularly relevant in settings where rare disease expertise is limited.[9]

Increasing awareness of aHUS within the paediatric nephrology community, alongside education and collaboration with organisations such as IPNA, may help shorten the path from first presentation to specialist assessment.

Alexion is committed to supporting education, scientific exchange, and collaboration to help raise awareness of recognising aHUS in children.

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**Alexion**, AstraZeneca Rare Disease, is focused on serving patients and families affected by rare diseases and devastating conditions through the discovery, development, and delivery of life-changing medicines. A pioneering leader in rare disease for more than three decades, Alexion was the first to translate the complex biology of the complement system into transformative medicines, and today it continues to build a diversified pipeline across disease areas with significant unmet need, using an array of innovative modalities. As part of AstraZeneca, Alexion is continually expanding its global geographic footprint to serve more rare disease patients around the world. It is headquartered in Boston, US.

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**Sobi**

## Time matters: early and accurate diagnosis of paediatric C3G and primary IC-MPGN

Diagnostic labels for complement 3 glomerulopathy (C3G) and primary immune complex-mediated membranoproliferative glomerulonephritis (IC-MPGN) have evolved from histological morphology to reflect growing understanding of disease pathogenesis.[1] C3G and primary IC-MPGN are two complement-mediated diseases driven by complement 3 (C3) dysregulation and excessive glomerular C3 deposition.[1–3] On immunofluorescence, C3G shows dominant C3 staining (≥2 orders of magnitude greater intensity than other reactants), while IC-MPGN shows co-dominant C3 and immunoglobulins.[2,4]

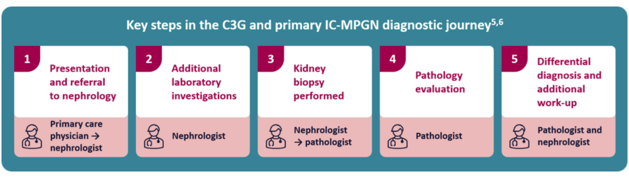
Clinical presentation of both diseases is heterogeneous and overlaps with other glomerulonephritides, making kidney biopsy necessary for definitive diagnosis.[5,6] At presentation, estimated glomerular filtration rate (eGFR) is normal or mildly lowered in >50% of paediatric cases;[7–9] however, disease course varies and early kidney damage can be silent.[10–12] Approximately 1 in 7 children experience kidney failure within ~5 years of diagnosis.[7,9,13] Since chronic damage is associated with higher kidney failure risk, early diagnosis is essential to allow intervention before irreversible damage occurs.[14–17]

For timely diagnosis, biopsy should be prompted by persistent proteinuria ≥0.5 g/day as per immunoglobulin A nephropathy guidelines, with or without reduced eGFR, haematuria, unexplained hypertension and/or low serum C3 levels for >3 months (excluding transient changes with postinfectious glomerulonephritis).[5,18,19] Normal serum C3 levels are seen in <25% of paediatric cases and do not rule out a diagnosis.[5,7,8]

Gold standard biopsy examination involves light microscopy, immunofluorescence and electron microscopy, so it is important that sufficient tissue is available for each modality.[20] Expert nephropathology evaluation is valuable.[20]

Multidisciplinary collaboration is key to confirming a diagnosis of C3G or primary IC-MPGN,[4,21] which requires exclusion of secondary causes of C3 deposition, including infections, autoimmune disease, monoclonal gammopathy and other neoplasias.[20]

As complement-targeted treatments emerge, early diagnosis and intervention is increasingly important.[2,3,17,22,23] Sobi is proud to be a committed partner at the forefront of supporting patients living with rare renal diseases.


Key steps in the C3G and primary IC-MPGN diagnostic journey[5,6]
1
Presentation and referral to nephrology
Primary care physician → nephrologist
2
Additional laboratory investigations
Nephrologist
3
Kidney biopsy performed
Nephrologist → pathologist
4
Pathology evaluation
Pathologist
5
Differential diagnosis and additional work-up
Pathologist and nephrologist

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## IPNA 2027 Kyoto – Record-Breaking Abstract Submission Numbers

We are delighted to share an exciting update on **IPNA 2027**, as the response from the global paediatric nephrology community has been truly remarkable. With **more than 1,300 abstracts submitted**, this marks a record-breaking number of submissions for an IPNA Congress and reflects the strength and diversity of research and collaboration across our community.

We extend our sincere thanks to everyone who has contributed to this outstanding scientific programme. We look forward to bringing colleagues from around the world together in **Kyoto, Japan, from 9–13 March 2027**, for an inspiring programme of scientific exchange, discussion, and shared learning.

There is still an opportunity to contribute to the Congress through the **Late-Breaking Abstract Submission**. **Submissions will open on 29 September 2026 and close on 12 October 2026**. Clinical trial abstracts will be prioritised for consideration, while the Scientific Chairs will also consider other research abstracts for poster presentation, providing an opportunity to share important new findings that have emerged since the main abstract submission deadline.

The Congress programme will offer a wide range of opportunities for learning and interaction, including **10 Pre-Congress Courses, 10 Breakfast Sessions, 10 Symposia and 14 Mini-Symposia, 40 Moderated Poster Walks, 6 Workshops, 3 Debates, 2 Innovation & Industry Sessions, and 6 Lunch Industry Symposia**. In addition, the **IWDN Post-Congress Workshop** will take place from **13–16 March 2027**.

We warmly invite the IPNA community to join us in Kyoto for this important gathering and to be part of a Congress that brings together the latest advances, ideas, and perspectives in paediatric nephrology.

**Early registration closes on 1 December 2026. We look forward to welcoming you to Kyoto!**

John D Mahan, MD
IPNA Treasurer

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9–13 March 2027
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Japan
Kidney Organoids: Disease Modelling and Future Transplantation

Tatsuo Kawai
USA
Xenotransplantation: A New Era in Organ Transplantation

Hui-Kim Yap
Singapore
Dialysis: Dialysis in Developing Countries

Record Number
1,300 abstracts submitted – a record number for any pediatric congress

Participation from over 80 countries

More than
More than 260 congress speakers

1 December 2026
EARLY REGISTRATION DEADLINE
For details on registration fees and categories, scan the QR code and benefit from the early registration rate.

## IPNA aHUS Guidelines Announcement

We are pleased to announce the launch of the **IPNA Guidelines on Atypical Hemolytic Uremic Syndrome (aHUS)** on **24 September — International aHUS Awareness Day!**

The new guidelines, published in Pediatric Nephrology, provide up-to-date guidance to support the diagnosis and management of children and young people living with aHUS.

The guidelines are now available here

## Spotlight on people living with rare kidney diseases at IPNA 2027