

# IgAN Alliance Stakeholder Collaborative Workshop 1 Topline Summary

September 7-9, 2025, Chicago, Illinois

## What was the purpose of the IgAN Alliance Stakeholder Workshop?

The IgAN Alliance is a collaborative effort to increase awareness and drive informed care to improve the diagnostic journey and management experience for people living with IgA nephropathy (IgAN) – a disease that is not often diagnosed or treated as early as it could be. Made up of advocacy organizations, industry partners, healthcare professionals, and IgAN community members, the IgAN Alliance was formed with the hope of shifting the culture in medical practice and empowering patients to advocate for timely testing and treatment of IgAN.

Despite advances in understanding of IgAN and the availability of approved, disease-modifying therapies, patients with IgAN face considerable barriers to timely diagnosis, informed decision-making, and access to care. To surmount these barriers, patients need to be educated about the disease and available treatment options, and must be empowered to access:

- clinicians who focus on glomerular diseases and understand IgAN
- clinical trials
- approved therapies
- support systems and groups

The IgAN Alliance seeks to unite leading companies, clinicians, patients, and other key stakeholders to address these gaps and accelerate progress toward more equitable, informed, and timely care. Informed by patient, caregiver, and physician survey results, the Stakeholder Collaborative Workshop provided a dedicated space to prioritize urgent access issues, share cross-stakeholder insights, and develop practical, collaborative solutions that can improve the patient journey and advance the standard of care.



To learn more about NephCure or the IgAN Alliance, scan this QR Code



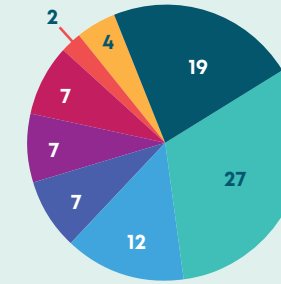
## Workshop Goals

The workshop goals were informed by findings from surveys administered to patients and caregivers, and from physician advisory board meetings. The workshop goals were to:

- Assess access challenges, cross-stakeholder needs, and prioritize solutions for access barriers across the IgAN community
- Elevate stakeholder voices by sharing real-world community experiences and insights to inform IgAN alliance priorities
- Understand ways to expand community education around timely diagnosis and informed treatment decisions
- Support innovation by identifying strategies to improve clinical trial recruitment and participation
- Establish solutions-focused working groups to begin drafting actionable strategies for post-workshop progress

## Attendees

The IgAN Alliance Stakeholder Collaborative Workshop convened 85 stakeholders who represented a wide range of roles across the care spectrum:



- Access Experts (2)
- Clinicians (19)
- Government (7)
- Industry (27)
- Patient organizations (12)
- Patients/Caregivers (7)
- Professional societies (7)
- Other (4)

## Key Topics Discussed

- The Patient Journey: Understanding the Barriers
- Urgency in Diagnosis: Biopsy vs. Watch and Wait
- The Care Triad: Patient, Physician, Specialist
- Access to Newly Approved Therapies: Understanding the Challenges
- Defining Value, Generating Evidence
- Navigating Insurance, Prior Authorizations, and Appeals
- Continuing Innovation: Clinical Trial Access and Enrollment, Regulatory/Policy Landscape

## Key Takeaways

- The Workshop participants expressed urgency on the need to:
  - advance education on diagnosis and treatment, facilitating earlier kidney biopsy
  - increase screening in targeted populations
  - improve access to therapies and specialized care; and
  - share data throughout the IgAN community
- Stakeholders committed to establishing collaborative working groups focusing on:
  - Urgency in Diagnosis: identify patients earlier and connect to optimal care
  - Urgency to Treat: ensure physicians understand and consider novel therapies
  - Evidence Generation: build confidence and guide care decisions, improve reimbursement case
  - Improve Access: support patients in obtaining the care they need and deserve

*A manuscript reflecting more detailed outcomes of the workshop is under development for potential publication in 2026.*

To express interest in joining a working group, scan this QR code



## Acknowledgements

**HOSTS:** NephCure

**CHAIRS:** Richard Lafayette, MD, Myda Khalid, MD, Luis Sanchez Russo, MD

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