

2025 National Conference Agenda

September 26th -28th, 2025

Calgary Central Library
800 3 Street SE, Calgary, Alberta



Friday

5:00pm Welcome & Cocktail Reception
at the Downtown Calgary Hilton Garden Inn

7:00pm End of Reception



Saturday - AM

7:00am Registration & Breakfast

9:00am Opening Session

9:30am Research 101: Setting the Stage

10:00am Coffee Break

10:30am Keynote Address: SID & PID

11:30am Partnering in Research: The Role of Patients
& Families

12:15pm Lunch Break

Saturday - PM

1:15pm Understanding the Patient Registry: Why Your Participation Matters

2:00pm New Avenues in Diagnostics & Treatments:
The Use of AI

2:45pm Coffee Break

3:15pm Nurse Advisory Committee Session: Topic
TBA

4:00pm Closing Session

4:30pm End of Day One

Sunday

9:00am Welcome to Day Two

9:15am Keynote Address: Dr. Donald Kohn & Dr. Paul Ayoub – The Future of Gene Therapies Supported by Innomar

10:15am Coffee Break

10:30am Your Gut Microbiome & Immune Health

11:30am Research Update

12:15pm Transforming DNA into Music: Where Science Meets Art

1:15pm Closing Session

1:30pm Family Picnic at Alberta Children's Hospital

Friday, September 26th

5:00pm **Welcome Cocktail Reception**

7:00pm

Kick off the conference and join us for the Welcome Cocktail Reception - a relaxed event with cocktails/mocktails, light bites and great conversation. This is a perfect opportunity to reconnect with people, meet new attendees, and ease into the weekend ahead. Whether you're a first time participant or a returning guest, we invite you to raise a glass and help us toast the start of an exciting and inspiring conference



Saturday, September 27th

7:00am Registration & Breakfast

Start your day by checking in at the registration desk to pick up your name badge and conference materials. Enjoy a complimentary breakfast and take this opportunity to network with fellow attendees before the sessions begin.

9:00am Opening Session

Join us as we kick off the conference with a warm welcome from our organizers and a brief overview of the day ahead. This session will set the tone for the event, highlight key themes, and introduce our special guests.

*Brent Leonard, Chair, ImmUnity Canada ; Dr. Stephen Betschel, Co-Chair
Immunity Canada Medical Science Advisory Committee, Special Guest Matt
Jeneroux, M.P. Edmonton-Riverside*



9:30am Research 101: Setting the Stage

Curious about research? Want to know more about the different types and what is involved? This introductory session breaks down the basics of research in a clear and accessible way.

Dr. Vy Kim, Hospital for Sick Children; Dr. Nicola Wright, University of Alberta; Taila Hartley, Care4Rare (TBC); Moderated by Duane Schreiner

10:00am Coffee Break

Take a short break to recharge with coffee, tea, and light snacks. This is a great time to stretch, connect with other attendees, and prepare for the next session.



10:30am Keynote Address: SID & PID

Join us for a compelling keynote by Dr. Silvia Ramón Sánchez, an expert in immunology, as she explores the complexities of secondary and primary immunodeficiency. Dr. Sánchez will discuss how these conditions differ, the latest advances in diagnosis and treatment, and the real-world impact on patients and families. This session offers valuable insights for anyone affected by or interested in immune system disorders.

Dr. Silvia Ramón Sánchez, head of the department of clinical immunology, Hospital Clínico San Carlos, Madrid

11:30am Partnering in Research: The Role of Patients & Families

Patients and families bring vital lived experience to research—shaping priorities, improving study design, and ensuring outcomes that truly matter. This session will explore meaningful ways to get involved in the research process, from idea generation to knowledge sharing. Hear from patient partners, researchers, and caregivers about how collaboration leads to more impactful and relevant research.

12:15pm Lunch Break

Enjoy a complimentary lunch and take time to relax, connect with fellow attendees, and reflect on the morning sessions. Dietary accommodations will be available.

1:15pm Understanding the Patient Registry: Why Your Participation Matters

Learn how the Canadian Inborn Errors of Immunity National Registry (CIEINR) is helping to advance research, improve care, and inform policy for individuals living with immunodeficiencies. This session will explain what the CIEINR is, how patient and family data is used responsibly, and why your voice and participation are essential. Hear from researchers and patient partners about the real-world impact of joining the registry.

- Update on the CIEINR - Dr. Beata Derfalvi, IWK
- Patient & Family Engagement Fundamentals in Patient Registries, Deborah Marshall and Gillian Currie (virtual)
- CIEINR - Initiatives, Challenges, Future Directions - Dr. Tamar Rubin, CHRIM; Dr. Sneha Suresh, University of Alberta

Moderated by Judith Maily-MacDougall



2:00pm New Avenues in Diagnostics & Treatments: The Use of AI

Discover the latest breakthroughs in diagnosing and treating primary immunodeficiency. This session will highlight cutting-edge technologies, innovative therapies, and emerging research that are transforming patient care. Experts will share insights into how these advances are improving outcomes and quality of life for individuals living with primary immunodeficiency.

Dr. Muhammad Mamdani, St. Michael's Hospital
Manish Butte, UCLA.

Moderated by: Dr Hugo Chapdelaine

2:45pm Coffee Break

Take a short break to recharge with coffee, tea, and light snacks. This is a great time to stretch, connect with other attendees, and prepare for the next session

3:15pm Nurse Advisory Committee Session: Topic TBA

Join the Nurse Advisory Committee as they share their unique perspectives on patient care, advocacy, and support within the immunodeficiency community. This session will highlight nursing-led initiatives, best practices, and opportunities for collaboration to enhance the patient and family experience.

4:00pm Closing Session

4:30pm

As the day draws to a close, join us for a reflective wrap-up highlighting key takeaways, inspiring stories, and next steps. This session offers a chance to celebrate our collective progress, share final thoughts, and look ahead to Day 2.



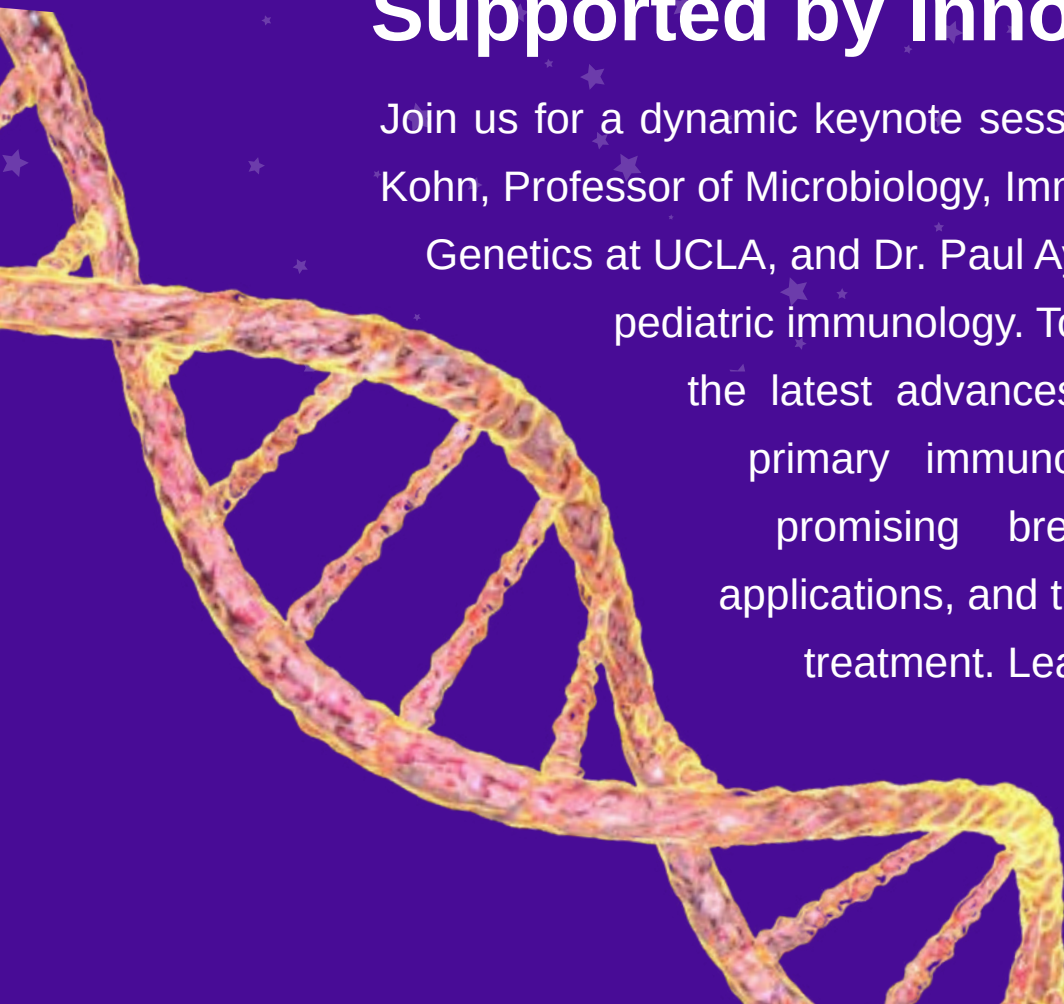
Sunday, September 28th

9:00am Welcome to Day Two

Start your second day with a warm welcome and overview of what's ahead. We'll highlight key sessions, share important announcements, and set the tone for another inspiring day of learning and connection.

9:15am Keynote Address: Dr. Donald Kohn & Dr. Paul Ayoub – The Future of Gene Therapies Supported by Innomar

Join us for a dynamic keynote session featuring Dr. Donald Kohn, Professor of Microbiology, Immunology, and Molecular Genetics at UCLA, and Dr. Paul Ayoub, a leading expert in pediatric immunology. Together, they will explore the latest advances in gene therapies for primary immunodeficiency, highlighting promising breakthroughs, real-world applications, and the path from research to treatment. Learn how these innovative approaches are transforming lives and shaping the future of care.



10:15am Coffee Break

Take a short break to recharge with coffee, tea, and light snacks. This is a great time to stretch, connect with other attendees, and prepare for the next session

10:30am Your Gut Microbiome & Immune Health

Explore the powerful connection between the gut microbiome and the immune system in this fascinating session. Learn how gut health influences immune function, the role of the microbiome in immunodeficiencies, and emerging research on how modifying the microbiome could support better outcomes for patients.

Dr. Emilia Liana Falcone, Director of the Microbiome Research Core at the Université de Montréal

Moderated by: Julia Hews-Girard



11:30am Updates in Research

Hear from Dr. Kevin Lee, recipient of the ImmUnity Canada Immunology Resident Research Grant, as he shares findings from his study: Understanding the Needs and Barriers to Care of Adolescents and Young Adults with Primary Immunodeficiency in Canada. This session will highlight key insights into the unique challenges faced by this age group and discuss implications for improving transitions in care and support services. This session, Dr Nicola Wright will give an overview of her groundbreaking gene therapy trial for CD3 SCID and the potential implications for this innovative approach for both patients and Canada. Don't miss the opportunity to hear about one of the most promising advances in precision medicines happening on our doorstep!

Hear from Dr. Kevin Lee, recipient of the ImmUnity Canada Immunology Resident Research Grant, as he shares findings from his study: Understanding the Needs and Barriers to Care of Adolescents and Young Adults with Primary Immunodeficiency in Canada. This session will highlight key insights into the unique challenges faced by this age group and discuss implications for improving transitions in care and support services.

12:15pm Transforming DNA into Music: Where Science Meets Art

Discover a unique fusion of science and creativity in this interactive session on translating DNA sequences into music. Learn how genetic information can be transformed into sound, offering a new way to understand and experience the human genome. This session explores the intersection of data, identity, and artistic expression—showcasing how music can make complex science more accessible and emotionally resonant. As featured on Season 3 of Immunity Canada's Life of PI podcast.

Dr. Michael Frishkopf, University of Alberta

Moderated by: Paola Andrea Fernandez de Soto Abdul-Rahim



1:15pm Closing Session

Join us as we wrap up the conference with final reflections, key takeaways, and a look ahead. We'll celebrate the connections made, the knowledge shared, and the collective progress toward improving care and understanding of immunodeficiency. Thank you for being part of this inspiring gathering—we look forward to continuing the journey together.

Brent Leonard, Chair and Dr. Bruce Ritchie, MSAC Co-Chair



1:30pm **Family Picnic**

All attendees are invited to join ImmUnity Canada, CINC and the Alberta Children's Hospital for an afternoon picnic directly after the conference. This family friendly event is supported by Pharming and Chiesi Global Rare Disease.

Transportation from the event venue will be provided.

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