

Hematology/ Immunology Research Retreat

June 7, 2024

Alberta Children's Hospital, Calgary, AB



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**Event
Overview**

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Event Overview

Name	Hematology/Immunology Research Retreat
Date & time	June 7, 2024 2:00 p.m. - 4:00 p.m.
Location	Alberta Children's Hospital

Goals & Objectives

The primary goal of the Hematology/Immunology Research Retreat was to bring together the research community to foster collaboration and knowledge exchange. The retreat aimed to provide a platform for researchers to present their ongoing studies, discuss current challenges, and explore potential solutions.

The specific objectives of the retreat were as follows:

- **Promote Collaboration:** Facilitate networking and collaboration among researchers in the fields of hematology and immunology.
- **Share Current Research:** Provide an opportunity for researchers to present their ongoing studies and receive feedback from their peers.
- **Identify Challenges:** Discuss the challenges being faced in various research projects, such as patient enrollment, data management, and clinical burdens.
- **Develop Solutions:** Generate ideas and strategies to overcome the identified challenges and improve research outcomes.
- **Plan for the Future:** Based on the discussions and outcomes of the retreat, identify the next steps for the research community to advance hematology and immunology research.

Through achieving these objectives, the retreat aimed to enhance the quality and impact of research in the fields of hematology and immunology.

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Speakers



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Speakers

Rav Chana, RN

Alice Laut, RN

Dr. Mac Steele

Hanna Huska

Dr. Nikki Wright

Dr. Luis Murguia

Dr. Aru Narendran

Dr. Greg Guilcher



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**Executive
Summary**

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Executive Summary

The Hematology/Immunology Research Retreat held on June 7, 2024, successfully brought together the research community to foster collaboration, share insights on current projects, and address challenges being faced in the field. The retreat served as a platform for researchers to present their ongoing studies, spanning a wide range of topics including inherited marrow failure, aplastic anemia, bleeding disorders, inborn errors of immunity, and sickle cell disease.

Key challenges identified during the retreat included patient enrollment, data management, clinical burdens, and participant eligibility. The retreat facilitated productive discussions on these issues, leading to the identification of potential solutions. The retreat also highlighted the importance of research infrastructure, with discussions on Phoenix, a clinical research infrastructure that provides funding and support to advance pediatric clinical trials and access to innovative therapies in the Hematology/Oncology/Transplant/Immunology program.

Overall, the retreat achieved its goal of fostering a sense of community among researchers, promoting knowledge exchange, and facilitating problem-solving discussions. The insights gained and action points identified during the retreat will guide the next steps in hematology and immunology research.



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Agenda

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Agenda

2:00 - 2:10 p.m.	Introductions
2:10 - 2:30 p.m.	Canadian Inherited Marrow Failure Registry (CIMFR) and Canadian Aplastic Anemia Study (CAMS) presented by Rav Channa and Alice Laut Bleeding disorder study presented by Hanna Huska Autoimmune Hemolytic Anemia Study presented by Mac Steele
2:30 - 2:45 p.m.	PIDTC (6908, 6907, 6906) presented by Nikki Wright and Luis Murguia
2:45 - 3:00 p.m.	Sickle Cell Disease Study presented by Aru Narendran
3:00 - 3:15 p.m.	PHEONIX presented by Greg Guilcher
3:15 - 4:00 p.m.	Discussion: <ul style="list-style-type: none">· Registries / Clinic Databases· Sickle Cell Registry - GRNDad: Greg<ul style="list-style-type: none">· Potential resources for GRNDad· CIEIN Registry for immune deficiency<ul style="list-style-type: none">· Clinic database, other registries.· How much can we collect from Connect Care?· Future research plans and goals for Hematology/ImmunologyImproving research engagement and study participation with Hematology/Immunology patients

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**Session
Summaries**

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Session Summaries

- 1. Canadian Inherited Marrow Failure Registry (CIMFR) and Canadian Aplastic Anemia Study (CAMS):** The focus was on data collection and clinical study of inherited marrow failure and aplastic anemia. Challenges included limited patient enrollment numbers, keeping patient data up-to-date, and difficulty identifying eligible patients. Action items included discussion regarding enrolling patients from other centers referred to Calgary for BMT and updating data entry and collection.
- 2. Bleeding Disorder Study:** The objective of this study was to assess the quality of life in adolescents experiencing heavy bleeding. Challenges included ensuring adequate patient numbers across sites and engaging adolescent participants over the follow-up period.
- 3. PIDTC Studies (6907, 6908, 6906):** These studies aimed to assess the outcomes of inborn errors of immunity before definitive therapy, analyze outcomes post-transplant or gene therapy, and better understand the presentation, outcomes, and treatments of primary immune regulatory disorders. Challenges included consistently collecting stool samples for microbiome analysis and the broad eligibility criteria.
- 4. Sickle Cell Disease Study:** The study assessed the use of different treatment options for Sickle Cell Disease to improve children's outcomes.
- 5. PHOENIX:** The Pediatric Hematology/Oncology Experimental and Novel Therapeutic Excellence Project (PHOENIX) is an ACHF investment in clinical research for the HOTI program. This generous investment is largely to fund personnel for infrastructural support for the Clinical Research Unit (CRU), to increase the number of children and adolescents who have access to clinical research studies. Priorities include clinical trials for hard-to-treat cancers and serious blood disorders, local investigator-initiated studies and single-patient studies. PHOENIX aims to enhance access to clinical trials, novel therapies and research studies through key personnel hires such as a CRU coordinator, clinical research associates, clinical research nurses, data entry specialists, research pharmacy support, an innovative therapies access navigator and administrative professionals.
- 6. Sickle Cell Registry—GRNDaD:** GRNDaD is a North American sickle cell disease registry that collects data on patients with sickle cell disease. Overall, agreement was reached on opening a GRNDaD registry in Calgary. However, concerns were raised about increased clinic burdens; suggestions offered were to have CRN help, look into general consent forms, or set patients in separate rooms while filling out forms.
- 7. Clinical Database and Registries:** Discussed challenges in accessing patient data and outcomes from ConnectCare due to issues with data quality and how information is captured. Action points included further exploring data extraction capabilities from Connect Care for research.



**Next Steps &
Discussion
Points**

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Next Steps & Discussion Points

- 1** Consider Clinical Burdens: Evaluate the impact of research activities on clinical workloads. Look for ways to streamline processes, improve efficiency, and reduce burdens where possible. Discuss buying an iPad for the clinic for patients to efficiently complete patient/family questionnaires.
- 2** Increase Knowledge of Eligible Participants: Work on improving awareness and understanding of the criteria for participant eligibility in studies. This could involve training sessions, informational materials, or regular communications about ongoing studies.
- 3** Improve Data Management: Address the challenges identified in data collection, entry, and updating. Consider implementing new systems or processes to improve data accuracy and completeness.
- 4** Enhance Patient Enrollment: Develop strategies to increase patient enrollment in studies. This could involve outreach to other centers, e.g. having Edmonton and SK open the studies, improved patient identification processes, or initiatives to make participation more appealing or convenient for patients.
- 5** Strengthen Collaboration: Foster stronger collaboration with other centers and within teams. Sharing knowledge and resources can help to overcome challenges and improve outcomes.
- 6** Explore New Research Areas: Based on the discussions at the retreat, consider exploring new areas of research, such as the potential of fecal transplants/microbiome for inflammatory disease treatments.
- 7** Invest in Infrastructure: Consider investments in research infrastructure, such as hiring a drug/therapies access navigator, to support the advancement of pediatric clinical trials and access to innovative therapies.
- 8** Standardize Clinical Details Capture: Develop standardized templates for capturing clinical details like diagnoses and treatments in patient problem lists. This can help improve data quality and extraction capabilities for research.

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Conclusion

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Conclusion

The Hematology/Immunology Research Retreat was a significant step forward in fostering collaboration and addressing key challenges within our research community. We discussed a wide range of topics, from inherited marrow failure and aplastic anemia to bleeding disorders and inborn errors of immunity. The retreat underscored the importance of research infrastructure, with enlightening discussions on Phoenix, a clinical research infrastructure that advances pediatric clinical trials and innovative therapies

The insights and action points identified during the retreat will guide our next steps in hematology and immunology research. We look forward to continuing these discussions and collaborations, driving innovation, and advancing research in our field

We would like to thank Dr. Wright and the organizing team (Brenda, Tatiana, Hanna, Mithili) for their work in bringing us all together. A special thanks to all the presenters for sharing their insightful research and sparking productive discussions. Finally, we would like to express our gratitude to all the attendees for their active participation and valuable contributions.

Thank you all for making this retreat a success!



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