



Garrod Association | Association Garrod 2025-2026
Committee Annual Reports



The Garrod Association

The Canadian Association of Centres for the Management of Hereditary Metabolic Diseases
Association Canadienne des Centres de Traitement pour les Maladies Métaboliques Héritaires

4 Cataraqui Street, Suite 310, Kingston, ON K7K 1Z7

info@garrod.ca | www.garrod.ca

Committee: Grants and Awards Committee

Document: 2025-2026 Annual Report

Garrod Awards Program Report for 2025, for review at 2026 Annual Meeting – Anna Lehman

Members for 2025:

- Dr. Aziz Mhanni (Chair – last year)
- Dr. Anna Lehman – (Incoming Chair for 2026)
- Dr. Sarah Dyack
- Dr. Grant Mitchell
- Dr. Tony Rupar
- Dr. Neal Sondheimer

a. **Garrod Trainee Research Award:**

- i. Implemented in 2022. Two research awards are available per year, \$10,000 each.
- ii. The guidelines and application form are posted on the website.
- iii. Deadline is last Monday of October at 23:59.
- iv. Trainee Research Awards (2024):
Two applicants for the research award 2024 – neither qualified based on application criteria. No research awards advanced in 2024
- v. Trainee Research Awards (2025):
 - Azizia Wahedi (Supervised by Andreas Schulze)
 - Danielle Lynch (Supervised by Gabriella Horvath)

b. **Garrod Trainee Educational Award:**

- i. Award program to support trainees attending educational courses, implemented in 2023.
- ii. Four awards available per year, \$1000 each.
- iii. Guidelines are posted on the website.
- iv. Deadlines for submission are 4:00 pm on March 8th and September 15th each year.
- v. 2025: There were 6 applications received. Five applications were eligible and were granted the award. The sixth application was not eligible and was declined.
- vi. Recipients:
 - Joshua Dubland (CCMG Lab Biochem Fel)
 - Randa Sultan (CCMG Clinical Biochem Fel)
 - Manal Alnabulsi (CCMG Clinical Biochem Fel)
 - Manar Aldarwish (CCMG Clinical Biochem Fel)
 - Michael Mackley (RCPSC Medical Genetics Res)



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Members: Andrea C Yu, MD – CHEO (Chair), Michal Inbar Feigenberg, MD – Sickkids, Pranesh Chakraborty, MD – CHEO, Shaily Jain, MD – Edmonton, Graeme Nimmo, MD – UHN, Murray Potter, MD – Hamilton, Beth Potter, PhD – Ottawa, Sarah Dyack, MD – IWK Health Centre, Daniela Buhas, MD – McGill, Ingrid Tein, MD – Sickkids

Activity Updates

Updates to Garrod Association Website

- Reformat of Guidelines and Resources page for easier navigation
- Ensure all documents linked on site have been reviewed by Garrod
- AGREEII Appraisal Summaries Published
- General email for members to contact Guideline Committee

ER Letters Template Project

- Letters for all common diseases have been drafted
- Discrepancies between practises of different centres will be discussed to decide which to be included

If your centre has not submitted their Emergency Letters for this project and you would like to be included, letters can still be sent to: guidelines@garrod.ca.



Committee: Liaison and Relationship Committee

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Report to the 2026 AGM of the Garrod Association of Canada- May 2026

Members: Dr. Saadet Andrews, Dr. John Mitchell, Dr. Sandra Sirrs, Dr. Andreas Schulze, Dr. Sarah Dyack, Dr. Cheryl Rockman-Greenberg (Chair) with invaluable input from John Adams

Recent initiatives since last meeting

1) Update on Pegzilarginase (Recombinant human enzyme therapy) to treat ARG1-deficiency (ARG1-D)

- a. Submission to Canada's Drug Agency (CDA) made by Garrod and CORD by the Feb. 17, 26 deadline for clinician and patient submissions respectively.
- b. The draft CDA staff report went to sponsor (Immedica Pharma) on May 11, deadline to respond May 21.
- c. Scheduled to be considered by expert committee June 24, draft recommendation for public comment July 16 with deadline of July 30.
- d. Clinicians and patients will first learn of draft recommendations on July 16th.

2) Private Members Bill

- a. **MP Marcus Powlowski** (MP Thunder Bay and Rainy River) introduced a Private Members Bill on March 11th, 2026 to the House of Commons. He proposes the updates to Health Canada's **Special Access Program** to enable faster, notification-based access to certain evidence-supported therapies based on
 - i. Stronger recognition of **clinical judgment and real-world medical evidence**
 - ii. Clear requirements for **transparency and accountability** when access is denied
 - iii. Continued **safety monitoring and Ministerial oversight**
- b. Bill C-265 legislation aims to:
 - streamline access to well-established therapies
 - reduce repetitive administrative burden for clinicians and pharmacists, and
 - create more flexible, patient-centred pathways to innovative treatments.
- c. MP Powlowski just completed his second reading of *Bill C-265: An Act to Amend the Food and Drugs Act* in the House of Commons. During debate, all parties indicated willingness to support the Bill to progress to the next stage of the legislative process.
- Dr Cheryl Rockman-Greenberg and many organizations eg Rare-KIDS Can provided letters of support and input to MP Powlowski



- 3) **Health Canada has approved a third drug Sepiapterin for patients with PKU**
 - a. **Small molecule sepiapterin approved for patients with sepiapterin – responsive PKU 1 month of age and older**
 - b. Is a precursor to BH4
 - c. from PTC Therapeutics
 - d. Health Technology Assessment (HTA) with CDA and INESSS to begin May, 2026

- 4) **Proposed Modernization of Medical Foods regulations**
 - a. Consultation continuing with Health Canada which is proceeding with Cost benefit analysis - deadline to respond to survey July 31, 2026

- 5) **National Strategy for Drugs for Rare Diseases update**
 - i. This Federally funded three-year framework (Phase 1) was launched in March 2023 and is intended as a foundation for future, long-term strategies aimed at reducing inequalities in access to treatment for rare diseases across Canada. **Overall oversight provided by Implementation Advisory Committee which is to support roll out of the Strategy**
 - ii. \$1.5 billion over 3 years (April 1, 2024 and March 31, 2027)
 - iii. As key part of the Strategy, the Government of Canada signed bilateral funding agreements with all 13 provinces and territories. Funding is also provided to Indigenous Services Canada's Non-Insured Health Benefits Program to support eligible First Nations and Inuit patients living with rare diseases. Funding also to CDA, CIHI and CIHR for projects.
 - iv. Many different committees/subcommittees
 - v. Members of Garrod participate in several committees
 - vi. Screening & Diagnostics Committee active – 10% of \$ set aside for S and D

- 6) The House of Commons Health Committee is in midst of a study with public hearings on “Canada’s Pharmaceutical Sovereignty” aiming to reduce dependency on foreign drug supply chains, address shortages and strengthen domestic manufacturing.

- 7) The Federal Ministers of Health and Innovation, Science & Economic Development in March 2026 established a Task Force on the Pharmaceutical and the Life Sciences Sector. aiming to enhance Canada’s competitiveness and improve access to innovative medicines. It is meeting privately and is to report to the Ministers this summer.



Dr. Danielle Bourque

The Royal College Subspecialty in IMD Medicine

(IMDM) Report dated June 11, 2026

1. Background and Goals

The IMDM initiative was developed to address several workforce and professional challenges:

- Ensure appropriate recognition and compensation for IMD specialists.
 - Secure dedicated funding for training positions.
 - Increase visibility of IMDM through the CaRMS residency matching system.
 - Maintain a sustainable pipeline of future specialists.
 - Attract trainees from disciplines beyond Medical Genetics.
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2. Development Timeline of the New Subspecialty

The presentation outlines a multi-year process leading to full implementation:

Year	Milestone
2020–2021	Workforce survey and development of adult IMD competencies
2022–2023	Stakeholder engagement (CCMG, feeder specialties, etc)
2023	Application submitted for subspecialty recognition
June 2024	Official recognition of Adult and Pediatric IMDM subspecialties
June 2025 – April 2026	Royal College workshops to develop training objectives, EPAs, and accreditation standards Physicians Involved: Dr. Sandra Sirrs, Dr. Hanna Faghfoury, Dr. Danielle Bourque, Dr. Trudy Naismith, Dr. Shailly Jain, Dr. John Mitchell, Dr. Marisa Chard, Dr. Hugh McMillan
Spring–Fall 2026	Finalization and approval of accreditation standards
July 2027	Accreditation standards published; programs can apply for accreditation
July 2028	First trainees begin training (hopefully!)

3. Structure of the New Subspecialty

Physicians may enter IMDM training from several primary specialties:

- Medical Genetics
- Internal Medicine
- Pediatrics
- Pediatric Neurology
- Adult Neurology

Separate accreditation streams will exist for:

- Adult IMDM
- Pediatric IMDM

The expectation is:

- All seven current Canadian biochemical genetics training programs will seek pediatric accreditation.
 - Approximately 2–4 adult IMDM programs will be created.
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4. Competency-Based Training Model

Training follows the Royal College's competency-based framework consisting of four stages:

Stage 1: Transition to Discipline

- Approximately 1 month.
- Orientation, logistics, and assessment of trainee readiness.

Stage 2: Foundations

- Approximately 7 months.
- Brings trainees from diverse backgrounds to a common competency level.

Stage 3: Core Training

- Approximately 15 months.
- Majority of specialty-specific learning and clinical exposure.

Stage 4: Transition to Practice

- Approximately 1 month.
- Preparation for independent clinical practice.

This competency-based training program includes 24 Entrustable Professional Activities (EPAs), which are the specifically evaluated tasks of the discipline. There are two EPAs that are program specific: ***Management of the IMD patient through pregnancy (adult only)*** and ***Managing a neonate with a positive newborn screen (peds only)***. The remaining EPAs are present in both streams (e.g. ***Managing the patient requiring hospitalization with an acute metabolic decompensation***) and will be evaluated in a specific context (e.g. managing acute liver disease in an adult vs managing acute hyperammonemia in an infant).

5. Certification and Exam Eligibility

Practice Eligibility Route for Subspecialists (PER-SUB)

Intended for:

- Physicians licensed in Canada.
- Currently practicing in the subspecialty.
- Individuals without recognized formal subspecialty training.

This pathway is expected to apply to many currently practicing CCMG-trained IMD physicians.

Practice Eligibility Route for Subspecialty Examination Affiliate Program (PER-SEAP)

Intended for:

- Internationally trained IMD subspecialists.
- Physicians practicing continuously in Canada for at least two years.
- Individuals who are not Royal College-certified in their primary specialty.

Exam eligibility does not necessarily mean that physicians are required to write the examination.

6. “Grandfathering”

A special **Founder IMDM designation** will be reserved for:

- Chair of the Specialty Committee.
- Members of the Examination Committee.

Individuals serving in these leadership roles cannot simultaneously sit the IMDM certification examination or receive credentialing while serving. Volunteer recruitment for these committees is planned.