



GARROD ASSOCIATION ANNUAL GENERAL MEETING

MINUTES- OTTAWA, MAY 4, 2024

Start time: 13:00

Present: Attendance was documented on the sign-in sheet (archived, available on request) by 40 members

1. Motion to accept the Agenda

Proposed by Pranesh Chakraborty, seconded by Michael Geraghty – approved.

2. Motion to accept the 2023 AGM Minutes

Proposed by Gabriella Horvath, seconded by Aziz Mhanni – approved.

3. President's Report – Paula Waters

a. Executive committee:

Paula is finishing her two-year mandate as President.

Aziz Mhanni, who was Vice-President for the last two years, is our incoming President.

Jagdeep Walia is finishing his third and final two-year term as Secretary/Treasurer.

Kristin Kernohan has completed her one-year term as Symposium Officer. She is succeeded by Gabriella Horvath, who will serve until the 2025 symposium to be held in Vancouver.

The Executive met monthly by Zoom, and had other frequent communications mostly by email. Paula took the opportunity to thank all members of the Executive for their work and support throughout the last year, and to wish Aziz great success as he takes over the reins.

b. 2024 Symposium :

Paula expressed her appreciation to Kristin Kernohan, Danielle Bourque and Nathalie Lepage (co-chairs) and all other members of the local organising committee in Ottawa. She also thanked Darlene McCormack and her colleagues from McMaster CPD, including Carol Stewart and the travelling audio-visual team, for their invaluable contributions to the organisation of the symposium.

c. Board of Directors:

We currently have representatives (Directors) from 15 of the 16 'Academic Treatment Centres' which form the core of the Garrod Association. The only centre presently



lacking representation is University of Saskatchewan. It was excellent to have directors, or their designated replacements, from 14 of those centres present at our annual BoD meeting on Thursday evening. Occasional other BoD business during the year was conducted by email.

d. **Committees and Working Group:**

There are several active committees and working groups (see reports 8-11 below). Paula thanked all Chairs, presenters of reports and group members for their contributions to the Association.

e. **Garrod Association Website:**

Our Association Website has not been updated over the last year. Our Webmaster, Yusuf Yilmaz, was unwell - more seriously than we realised - and he passed away early in 2024. In his absence, we do not have access to modify the site content. Jagdeep has been working to restore access so that maintenance and updates of the site can resume.

f. **Communications:**

Paula sent a Newsletter to all members in December 2023 and has also sent various other communications to members by email throughout the year.

g. **Membership:**

We now have nearly 300 members, which is a new record. This reflects a continuing active drive to build up our membership, especially to encourage trainees and allied health professionals (who are eligible to be Regular Members) to join. The annual membership fee has still been kept very low, at \$30. The symposium registration fee structure is set up to provide an incentive, i.e. cheaper registration fees for all members versus those for non-members. It takes a lot of work to create and maintain an up-to-date and meaningful database and mailing list of members, and there is still more to do to improve this.

Paula reminded everyone that registering as a 'member' to attend a symposium, using the annual symposium Web platform (which is administered by McMaster CPD), does not automatically lead to becoming a member, as used to be the case many years ago. Anyone wishing to become a *new* member of the Association should send an email to president@garrod.ca (see the instructions and link on the Association Website), as a request to join. For *existing* members, if they attend the annual symposium their annual membership dues are included in the registration fee. If they are not attending the symposium in a given year, they should pay their annual dues on the Association Website. Reminders about this will be sent out.



h. Administrative Assistant:

We have recently taken on a part-time administrative assistant, Sherry Dugdale, who is currently learning the ropes. Sherry will provide support to the Executive, including work on the membership database and the Association Website.

i. Liaisons between Garrod Association and other societies:

- 1) SSIEM – our representative is Grant Mitchell.
- 2) SIMD – our representative is David Sinasac.

j. Future symposia and conferences:

- 1) The 2026 Garrod Symposium will be organised as a joint event together with the Canadian College of Medical Geneticists. The plan is to hold this in the Eastern Townships region of Quebec, with Paula leading the local organising committee and serving as a liaison between the Garrod Association and the CCMG.
- 2) It has now been confirmed that the 2029 ICIEM (International Congress of Inborn Errors of Metabolism) will be held in Toronto. The Garrod Association and SIMD together submitted a joint bid to the ICIEM International Organising Committee, which was successful. Congratulations go to Andreas Schulze, who is leading this initiative.

4. Finance Report - Jagdeep Walia

(Copy of slides archived, available on request)

- a. At the end of April 30, 2024, the Association had a balance of \$185,417.00.

5. Auditors:

(Copy of the Financial Audit Statement archived, available on request)

- a. After the Garrod AGM, the Finance report was audited by Pierre Allard and Lauren MacNeil, two Garrod members. Pierre Allard and Lauren MacNeil confirmed that the numbers were correct and they were satisfied that there were no omissions or other concerns. They completed a Financial Audit Statement on 2024-09-03.

6. Election of Vice-President/President-Elect for 2024-2026

Sarah Dyack has been approved by acclamation

7. Election of Secretary/Treasurer for 2024-2026

Nathalie Lepage has been approved by acclamation

8. Liaison and Relationships Committee Report – Cheryl Rockman-Greenberg

Activities over the past year focused on 2 initiatives



- a. Health Canada requested for feedback regarding their proposal on the restructuring/modernization of regulations regarding Foods for Special Dietary Purposes (FSDP) and not FSDP. John Adams (CanPKU) and Maria Depenweiller (Canadian nutrition specialist, advocate and active lead of CanPKU) provided us with a draft response regarding restructuring of the regulatory framework. Following input from the L and R committee, a response was sent jointly to Health Canada jointly from CanPKU+ and Garrod (attachment 1)
- b. The L and R committee responded to a request from Dr. Charlotte Moore on behalf on the Pediatric External Reference Group (PERG) established by Health Canada to advise on the development of a National Priority List of Pediatric Drugs (NPLPD). PERG was presented with a short list of 119 drugs submitted by stakeholders. 4/119 were considered in our field of hereditary metabolic disorders with a request to score and prioritize these 4 with respect to urgency.

All the nominated eligible drugs (N=4) pertaining to the GENETIC-METABOLIC DISEASES. Each drug belongs to one of these 3 categories

- i. *New drug category: drug not authorised by Health Canada (i.e. need to resort to the federal Special Access Program)*
- ii. *New indication category: drug available in Canada but lacking the requested evidence-based pediatric indication (while the requested pediatric indication is listed in a trusted foreign jurisdiction).*
- iii. *New formulation category: drug available in Canada but in need of a commercially available pediatric friendly formulation (when a pediatric friendly formulation is available in a trusted foreign jurisdiction).*

Consensus comments from our group:

All four should be considered urgent for each of their respective conditions. However we felt we should:

- Prioritize Hydroxocobalamin IV/IM first, as the new formulation would allow us to provide higher dose hydroxycobalamin of 20 mg, which is now felt to prevent the retinitis pigmentosa seen in methylmalonic acidemias better than 5mg/ml current formulation.
- Chenodeoxycholic acid (oral) - next highest priority, to fill unmet need - would be considered very high priority by pediatric gastroenterologists.
- Fosdenopterin IV - next highest priority, but the disorders which it is used to treat are exceedingly rare.
- Sodium benzoate - least urgent for IV use, as we believe Ammunol is approved in Canada and not just by special access.



Concerns expressed

All involved found it difficult to provide comparative rankings of the relative urgency for these four drugs, given that the clinical contexts and groups of disorders relevant to each drug are different from each other, and there were no defined criteria for weighting of different aspects. Also, while some individual members of the Garrod Association might have been contacted in the original round of consultations designed to solicit nominations of candidate drugs, the Association as an entity had not been involved (apparently was not consulted directly). As a result, it was felt that there were other drugs for other metabolic disorders which would have been equally important to consider in this process but which were not on the 'shortlist of four' because no-one had nominated them. In other words, the list which was presented to us for ranking was not comprehensive at the outset.

The group therefore wished to make it very clear that the four drugs which we have ranked, as requested, do not equate to "the four treatments considered most important by the Garrod Association

Members: Dr. Saadet Andrews, Dr. John Mitchell, Dr. Cheryl Rockman-Greenberg (Chair), Dr. Andreas Schulze, Dr. Sandra Sirrs, Dr. Paula Waters

Discussion during AGM.

- All Garrod members should contact the Garrod Executive when contacted by any national organizations and/or committees.
- The Implementation Advisory Group (Aneal Khan, Sandra Sirrs, Pranesh Chakraborty) is seeking feedback from all Garrod members' respective communities. To pursue the discussion, there will be a virtual meeting for Garrod members this Summer.

9. Guidelines Committee Report – Andrea Yu

- a. Highlights:
 - Evaluated 9 management guidelines using the AGREE II tool including:
 - All guidelines previously posted on the Garrod website: Tyrosinemia Type 1, PA/MMA, Glutaric Aciduria Type 1, Pompe, PGM1-CDG
 - Other guidelines: VLCADD, Cystathionine beta-synthase deficiency, Urea Cycle Defects, α -aminoacidic semialdehyde dehydrogenase deficiency
 - Started Emergency Management Letters Template Project
 - Projects currently on hold: PKU Management Guidelines; Gaucher Management Guidelines
- b. Challenges:
 - Main venue for disseminating work to membership is through the Garrod Association Website (difficulties with being able to update)

Members: Dr Daniela Buhas, Dr Pranesh Chakraborty, Dr Sarah Dyack, Dr Michal Inbar Feigenberg, Dr Shaily Jain, Dr Graeme Nimmo, Dr Beth Potter, Dr Murray Potter, Dr Ingrid Tein, Dr Andrea C Yu (Chair)



Discussion during AGM.

- Evaluation and endorsement of existing guidelines published by other groups is considered helpful – we should continue to do this. We should also consider adding notes/comments in our evaluations regarding how the suggestions can be applied/might be affected by our Canadian context.
- Since the target audience of our ER letters project are health professionals working in the ER, we should collaborate with existing groups which are already working on creating resources for ER health professionals
- Garrod should seek collaboration with a Canadian journal to publish peer-reviewed supplements with Garrod updated guidelines. This will enhance visibility for Garrod, and will ensure Garrod is recognized as a professional organization. Publications will also help to recognize the authors' contribution to the guidelines development and updates. Publications in a Canadian journal will also contribute to highlight differences in approach among countries.

10. Award Program Report – Aziz Mhanni

a. Garrod Trainee Research Award:

- i. Award program approved in 2021 and implemented in 2022. Three research awards are available per year, \$10,000 each.
- ii. A research award review committee was formed (Tony Rugar; Grant Mitchell; Sarah Dyack; Neal Sondheimer; Aziz Mhanni).
- iii. The guidelines and application form, and deadline for the application is posted on the website.
- iv. Starting in 2023, we considered a fixed deadline for the applications to be the first Monday of October every year.
- v. In 2023: Since there were no applications received by October 2nd, we extended the deadline to October 30th, 2023, with an e-mail reminder announcement. Three applications received before this deadline and all three were reviewed and granted the award.
- vi. Proposed changes to the Awards committee: Aziz will step down from the Awards committee. Dr. Grant Mitchell agreed to act as an interim Research Lead on the committee for one year. Dr. Anna Lehman agreed to serve on the committee. This would make the research committee membership to include: Tony Rugar, Neal Sondheimer; Sarah Dyack; Anna Lehman and Grant Mitchell (Lead).
- vii. Please note the information on the website needs updating. We will be working on this as part of the work being done on the Garrod website in general.

b. Garrod Trainee Educational Award:

- i. Award program to support trainees attending educational courses, approved in 2023 and implemented in 2023.
- ii. Four awards available per year, \$1000 each.



- iii. Guidelines were circulated via e-mail, and will also “be posted on the Website” when feasible.
- iv. Deadlines for Submission are 4:00 pm on March 8th and September 15th each year.
- v. In 2023: There were 3 applications received for the March deadline, and 2 applications for the September deadline. Although we had stated that only 4 awards would be funded, given the fifth eligible application, we decided to fund all.

c. **Garrod Trainee Travel Award:**

- i. The possibility of creating a third award program - to support trainees attending conferences - has been raised in the past, but is currently on the backburner.
- ii. Andreas Schulze encouraged prioritization of this, citing the networking value of trainees going to international meetings and the current substantial bank balance of the Garrod Association.
- iii. Paula noted that, although there is still a substantial balance, it is decreasing rapidly as there have also been considerable deficits in each of the last few years.
- iv. Aziz stated that we will consider working on introducing a Garrod Trainee Travel Award program, as new funds permit.

We did not make any progress in this regard. This proposal remains on our radar to consider and work on.

Discussion during AGM. The Garrod board of directors would like to facilitate donations by creating the Travel Trainee award fund. Any Garrod members could contribute to this fund.

11. RCPSC Subspecialty Training Working Group Report – Sandra Sirrs

The RC application committee would like to thank the Garrod Association members for their support of the project. Numerous members worked on the application itself while others worked to obtain support letters, network with stakeholders, and provide helpful feedback on the application. The Garrod Association also funded the \$14000 application fee.

Status of application – the application has progressed through multiple stages and was recently approved by the Committee on Specialties April 18, 2024. The next steps include the Committee on Specialty Education, Executive Committee of Council and then the Royal College Council. If there are no concerns raised by these next steps, voting at the level of the Royal College Council could occur by June but this timeline is not firm.

If the application is successful, then a RC specialty committee for IMD Medicine will be formed to work on standards of accreditation – e.g. Program requirements, competencies of training, EPAs etc. This will be a lengthy process (i.e.. 2 years or more). Typically, such committees have as many provinces represented as possible so there will be opportunities for many individuals to work on developing the program. Representatives from the other proposed feeding disciplines (pediatrics, internal medicine, neurology) may also be involved in this committee, which is a helpful way to start increasing the visibility of the discipline. There is considerable ongoing work by the CCMG program directors on competencies



and EPAs and this work will also be valuable for the RC process. Once those standards of accreditation are defined, then individual sites can review those and choose whether they wish to seek RC accreditation and, if so, if they wish to seek it for pediatrics, adults, or both. The information we have received from the CCMG to date has been that they plan to continue to provide the CCMG clinical biochemical genetics program.

Discussion on the separation of the adult and pediatric streams continues. It is likely that there will be fewer sites seeking accreditation for the adult program than for the pediatric program and this is similar to other RC subspecialties where there is an imbalance of pediatric and adult programs. Pediatric trainees will need adult exposure and vice versa as is usual for all subspecialties. Some pediatric programs will likely have capacity to meet the adult exposure requirements for pediatric IMD trainees at their own sites, even if they do not have the capacity or physical set up to run an adult IMD training program. The CCMG programs currently cooperate to provide exposure (e.g. Trainees can do rotations at larger sites etc.) and it is expected this will continue. Each program can decide how to handle this issue and such decisions will be easier once the standards of accreditation are defined.

If the RC application is successful, then multiple sites may be seeking accreditation at the same time. It is likely that there could be cooperation amongst the sites in preparing accreditation documentation to share the workload. It would be helpful for Garrod to consider supporting this process with limited admin support (e.g. To set up zoom meetings, format documents etc.). Such support would be time limited as programs will be eligible for university support if they are successful in receiving RC accreditation.

Feedback from stakeholders – as part of the process, many suggestions were received for projects which the Garrod executive could consider supporting. Some suggestions include:

1. Establishing a national “bank” of IMD talks which could be used at multiple sites to increase visibility of the specialty. There are opportunities to collaborate with the CCMG on this. Jagdeep Walia is already working on such a project.
2. Establishing a national academic half day program – this would reduce the burden of teaching on each individual site. This work could be done regardless of the status of the RC application as it would help with the teaching in the CCMG programs and there are opportunities to collaborate with the CCMG on this.
3. Survey of reimbursement for metabolic physicians – there are discrepancies with how physicians are paid across provinces and also within a province for physicians of different backgrounds. There are opportunities to collaborate with CCMG who have collected data on this, but additional data will be required as the CCMG data will not necessarily be complete for metabolic physicians who are not from a genetics background.
 - a. Information from such a survey could then be used to support applications within individual provinces to review reimbursement of metabolic physicians which might help recruitment and retention.



- i. If the RC application process is successful, there will be opportunities to approach provinces to have metabolic physicians paid at subspecialist rates, but this will need to be done province by province.

Members: Dr Danielle Bourque, Dr Daniela Buhas, Dr Pranesh Chakraborty, Dr Hanna Faghfoury, Dr Cheryl Greenberg, Dr Gabriella Horvath, Dr Shailly Jain, Dr Jonathan Kronick, Dr Anna Lehman, Dr Graeme Nimmo, Dr Sandra Sirrs (chair), Dr Andreas Schulze, Dr Paula Waters

12. Varia

The discussion started under agenda item - **Guidelines Committee Report** – Andrea Yu. Under agenda 12- Varia: The recommendation is as follows: Garrod Executive should pursue formal links with the Canadian Journal Clinical Biochemistry. This journal would be the home of the Symposium abstracts as well as the Garrod guidelines.

13. Conclusion

The meeting was adjourned at 14:00