



THE UNITED INDUSTRY VOICE FOR AUSTRALIAN GENOMICS

April 2025

Message from the CEO

Dear members and friends of InGeNA,

It's been a busy and energising start to the year as we continue our work to advocate, collaborate, and shape the future of genomics in Australia. One of the things I value most about InGeNA is the deep, diverse expertise across our network and the willingness of members to collaborate for impact. That spirit of collaboration has been especially evident in recent weeks.

Policy and Advocacy: Building Momentum

Our advocacy efforts have been front and centre, as we continue to shape and promote our policy positions. We've seen strong resonance with our call to expand the role of genomics in clinical practice, and this theme was clearly reflected during our recent member meeting, where Cancer Australia provided a valuable update.

We are actively engaged with government on two important fronts: the establishment of Genomics Australia and the broader policy framework review. Due to the timing of the federal election, the consultation on the policy review has been rescheduled. Our planned InGeNA Roundtable will now align with this process - stay tuned.

InGeNA has worked closely with our members and consumer advisory group to shape our 2025 Policy Position Statement—*Advancing Genomic Medicine in Australia*. View now on our [Website](#)

Recognising Shifts in the Genomics Landscape

We're entering a time of transition, with Australian Genomics and Melbourne Genomics wrapping up in June and December respectively. I want to especially acknowledge Clara Gaff and the Melbourne Genomics team for delivering a fantastic State of Clinical Genomics Day. The event was a clear testament to the years of foundational work driving clinical adoption in Victoria. If you haven't already, I highly recommend exploring their new clinical

implementation toolkit - an excellent [resource](#).

While in Melbourne, I also attended the Population and Precision Health Summit hosted by Oxford Nanopore. The international presentations reinforced the importance of diversity, inclusion, and equity in genomics.

It was also a pleasure to connect with so many of you at our Melbourne networking event - these face-to-face moments are invaluable. If you're planning to attend the **Inspird Showcase** in Brisbane later 29 May, we'll be hosting a networking event at its conclusion. We'd love to see you there.

Citizen Jury on Genomics in Newborn Screening

I was fortunate to attend a unique Citizen Jury on Genomics in Newborn Screening - an impressive example of everyday Australians engaging thoughtfully with complex issues. The facilitation was outstanding, and the jury should be proud of their considered deliberations. We look forward to sharing the final report and jury statement, which will help inform future public policy on genomics.

Thank you to Principal Investigators Sarah Norris and Stacy Carter, and to our HGSA partners Lauren Hunt and Professor Ronda Greaves, for the opportunity to be involved.

Global Reflections

While we continue to advocate for progress locally, it's worth acknowledging the significant developments abroad. Recent cuts to central health agencies in the U.S. - including the FDA and CDC - and the disbanding of their public health genomics programs have sent ripples across the global community. These decisions serve as a reminder of the importance of continued investment, leadership, and vision in genomics.

Looking Ahead

As always, thank you for being part of InGeNA's growing network. Your insights and expertise are critical as we navigate this dynamic space together. There's much to look forward to - and many opportunities to shape what comes next.

Warm regards,
Erin



Oxford Nanopore Summit with Prof. Jonathon Edgeworth, Nat Thorne and Erin



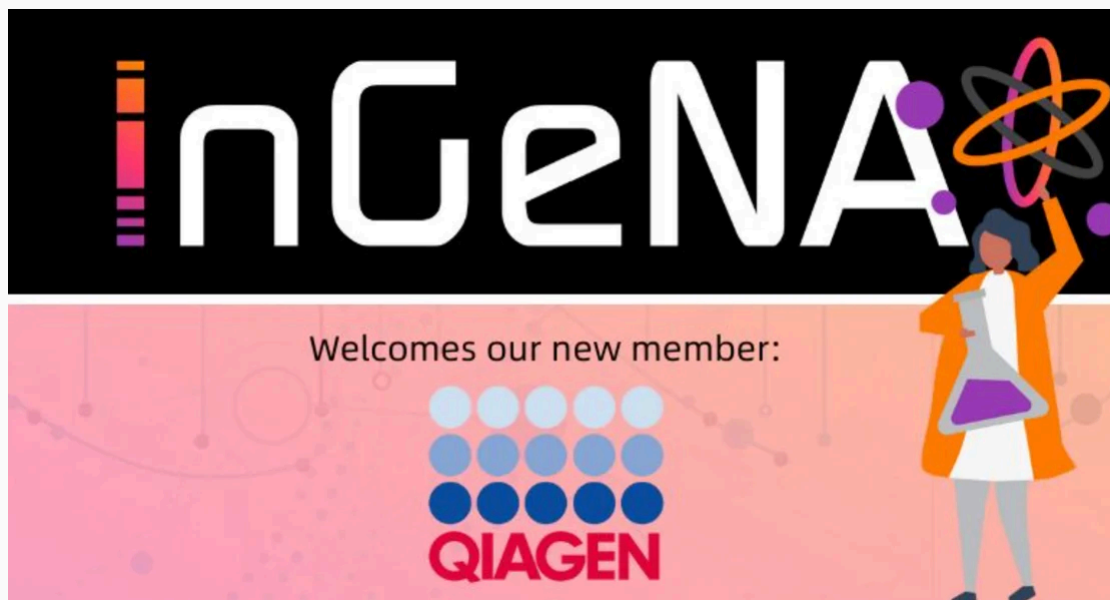
Citizen Jury: Erin with Lauren Hunt and Prof Ronda Greaves from HGSA.



Melbourne Genomics Summit: Jess & Joe from AGRF with Erin



Citizen Jury: Erin and Sarah Norris.



InGeNA welcomes QIAGEN as our newest member.

QIAGEN pushes the boundaries of innovation to improve our understanding of DNA, RNA and proteins – the building blocks of life. We enable our customers to unlock valuable insights from any biological sample – be it blood, a throat swab or many other materials. Our products for molecular testing serve a wide range of applications from basic life sciences research to clinical healthcare. Our reputation is based on confidence in decisions, clarity of results and pride in the insights our customers achieve. More than 35 Nobel Prize winners among more than 500,000 customers worldwide are proof of that success. Together, we are making improvements in life possible. **Read more about QIAGEN [on their website](#)**

Message from the Chair

Dear Members and friends of InGeNA,

As you will see from the April Newsletter InGeNA has had another productive and active month adding new members and continuing to accelerate access to genomics for Australian patients and their doctors.

We were delighted to have the opportunity to meet with members and InGeNA friends at our Melbourne networking event last month. Plans are underway for our next networking event to be held in Brisbane to coincide with Queensland Health's Genomics Summit on May 29th. More details will follow shortly.

Cheers
Carl

Upcoming Events

Tuesday April 1

All Day [GA4GH - April Connect](#)

Cambridge, Massachusetts, United States

<https://www.ga4gh.org/event/april-connect-2025/>

Tuesday May 6 – Thursday May 8

[AusMedtech 2025](#)

International convention and exhibition center, sydney

<https://www.ausbiotech.org/conference-information>

Tuesday May 13 – Wednesday May 14

[Digital Health Conference](#) - InGeNA presenting

Melbourne Victoria, Australia

Thursday May 29

All Day [Qld Health Genomics Forum](#)

Brisbane Convention & Exhibition Centre (Brisbane Queensland, Australia)

<https://www.eventbrite.com/e/genomics-inspird-showcase-tickets-1082741522039>

Thursday May 29 - 5pm

InGeNA Brisbane Networking Event

Industry News

Genomics Our Way' is now live!

[Australian Alliance for Indigenous Genomics](#) ALIGN has launched a groundbreaking no-cost online course designed to reshape Indigenous Australian genomics research.

This is the first course of its kind - centred on ethical research that prioritises Indigenous ways of knowing and doing. Led by experts with lived experience and strong community ties, it challenges how genomics research is taught, shared, and practised.

[Read more here](#)

The Cost-Effectiveness of Genomic Medicine in Cancer Control: A Systematic Lit Review

Expanding the current cost-effectiveness evidence base is essential to enable the sustainable and equitable translation of genomic medicine.

[Read more here](#)

Using implementation science to navigate the complexity of integrating genomics into healthcare

Australian Genomics led a country-level, longitudinal project to deliver and evaluate the impact of genomics in routine healthcare.

[Read more here](#)

World's first gene editing therapy now in the UK for sickle cell disease

The approval by NICE of Exa-cel provides new hope for people living with sickle cell disease.

[Read more here](#)

From the UK - PHG Foundation's EXPRESS study

Optimising EXome PREnatal Sequencing Services (EXPRESS) policy report outlines actions to enhance the clinical implementation and support further research into prenatal exome sequencing services within the NHS. It examines both the opportunities and challenges involved in establishing a new genetic testing service, while highlighting key findings - including insights from parents and healthcare professionals.

[Read more here](#)

CDC gutted including the public health genomics program

Among the casualties of these cuts is the public health genomics program. This was a small but mighty enterprise tasked with translating advances in human genomics and other technologies into population level actions that can improve health and prevent disease for all.

[Read more here](#)

Call for Feedback

From Australian Genomics

Tissue-targeted (somatic) genomic testing consent package.

Consultations are underway for a new patient consent package for tissue-targeted genomic testing. Tissue-targeted testing looks for somatic (acquired) genetic variants in tumour/lesion cells. It is used in various conditions such as cancer and vascular

anomalies.

The consent materials, developed by [hashtag#AustralianGenomics](#), can be found here: <https://lnkd.in/gQ6uWH8K>

Feedback is needed on the new tissue-targeted consent package to provide guidance for health professionals, patients and families. **Consultations close on 28 April.**

Individual Memberships now open

Individuals who are sole traders, researchers or students, can now join InGeNA. Individual Membership Brochure and Application form available on our [Website](#).



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