



A busy start to 2023!

There has been plenty going on in the program and the sector, earmarking an active start to the year for CaRE.

We have seen the awareness of the CaRE program steadily and continually increasing, which is leading to interest from new members. This includes people interested in joining the program from the community which is excellent. We are also proud to report this also includes interest from Monash University staff who are keen to develop, promote and accelerate community engagement in research.

We are thrilled to have started 2023 with strength, with our committee growing to a membership of 17, including **four community representatives!** We also welcome Dr. Arwel Jones to the role of Deputy Chair and extend our sincere thanks and gratitude to Dr. Loretta Piccenna for her ideas and efforts. Loretta is a true advocate for community engagement in research and made a tremendous impact on the program.

The committee has also welcomed the addition of new partnerships contributing to epilepsy, bowel cancer, and diabetes research. We're also strengthening community representation by building new partnerships with diverse community organisations and planning interesting community information sessions.

This energy we are witnessing within the Central Clinical School regarding community involvement

in research is not an isolated experience. We have also seen a lot happening in the sector. The Medical Research Future Funding has announced significant funding for community involvement in research, and several peak bodies and research institutes have been creating and recruiting community engagement positions within their organisations.

This progress towards more holistic medical research is heartening and motivating, and we are so excited to be a part of it!

Getting better together - CaRE reflection 2023

Yes, it's that time again...

A critical part of our program is understanding how we can continually improve. At CaRE, we do this by looking back over the last year to learn what worked well, and what can be better. **To do this, we need to hear from the most critical component of the program - YOU!** What has your experience of the program been? What would you like to see more of? What could be better?

The results of this reflection informs our planning and prioritisation process, and critically guides us to work towards strengthening community engagement in medical research. The results are also shared with the Central Clinical School's executive team, to showcase the great work we are doing, and the impact that you, our community members, are having on the day to day business of inventing new diagnostics, developing treatments, and finding cures!

Complete the Survey

This year, we are excited to announce that those who complete the survey also have the chance to win a \$50 Coles Group gift card! Don't miss your chance to enter the draw. The survey will close on 31 May 2023.

Principals assaulted

ALMOST a third of Victorian principals have been physically attacked by students or parents, a new survey has found.

School leaders had to deal with parents bypassing security protocols and coming on campus as well as threatening them at sporting matches and after hours events. ACU researcher and former principal Paul Killion said:



Libs bid to expel MP

OPPOSITION Leader John Pendergast will move to expel Myers Decaring from the Liberal caucus.

Mr. Pimental said Mr. Deming's appearance made her position "untenable". A move to expel her can't be put to the party soon before Friday because party rules require the

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Photo: Jack Bauer

Thanks A MILLION

More than 20,000 Victorians of all ages stepped up to raise \$1M in yesterday's Run for the Kids, with funds going to The Royal Children's Hospital Good Friday Appeal

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Run for Kids

EPILEPSY CURE HOPE

EXCLUSIVE Melbourne researchers to launch world-first trial of pill that halts seizures

MARTIN WILEY

A DAILY pill aimed at Melbourne more than a decade ago is being hailed as a potential cure for epilepsy.

The drug, known as sodium chloride, was originally developed by University of Melbourne researchers as a treatment for cancer. Now, it's world first. Australians will be among the first to try it, in a trial run by Monash University and The Alfred to see if it achieves the same success in treating epilepsy.

It means as if he cannot studies, **PAUL BOWMAN,**

DISCUSSION

A DAILY pill created in 1968, became more than a decade ago is being hailed as a potential

searchers as a treatment for cancer. Now, in a world first, 12 Australians will be enrolled in a trial run by Monash University and The Alfred to see if it

Take the
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Watch us on the Today Show!

A big WIN for CaRE!

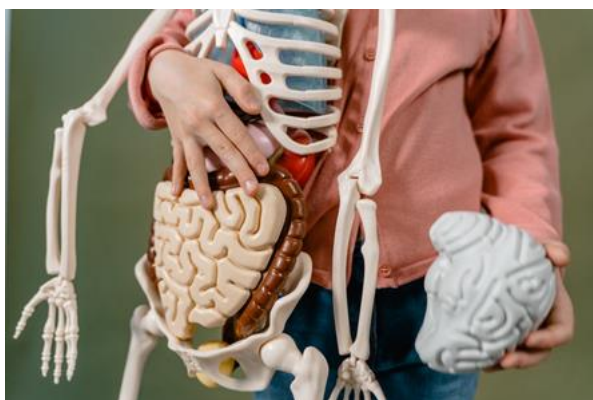
CaRE Researcher, Dr. Lucy Vivash, has demonstrated the power of community involvement in research! Lucy built on her experience of her ongoing CaRE partnership, and facilitated a focus group with 8 community members/advocates impacted by epilepsy.

The majority of the session included an open forum with a free-flowing discussion between the community members, considering the measures included in a pre-existing and commonly adopted 'desirability of outcome ranking' (referred to as DOOR) used in epilepsy trials. The group suggested alternatives and reordered the ranking. This means a more accurate measurement of quality of life of patients will be considered in an upcoming clinical trial Lucy and her team will be running. This clinical trial is as featured in the news articles

I thank you and congratulations to those of you who agreed to be part of Lucy's work - it has led to great success and innovation in Lucy's project! We are so proud that this initiative started with the CaRE program and are very excited about the commencement of the trial!

[Read the Herald Sun article](#)

Watch this space...



The CaRE Committee has been busy planning our next series of community information sessions.

We are pleased to announce that the overarching theme will be "The Brain", since it is such a critical and complex organ in the body, we hope to increase understanding of its function along with the role it plays in many diverse medical conditions.

The project team is keen to work with volunteer community members to shape and plan this seminar series. **If this is something you are keen to join, please email ccs.care@monash.edu.**

Refer a friend

We welcome participation by all community members impacted by the medical conditions we study.

Expressions of interest to join us, from community members are always accepted.

Additionally, we are **currently** seeking community representatives to join specific research projects including:

- POST SURGICAL PAIN

- BOWEL CANCER

[Know someone? Please share!](#)

[Express Interest Here](#)



Donate

Our research goals are to work with the community to develop better ways to diagnose, treat, care for and ultimately cure serious health conditions.

Some of today's modern research discoveries were only made possible by the support and generosity of donors. Every donation helps our research to progress and create discoveries.

How will my donation be used?

You can choose how we use your valuable contribution, by either supporting a disease or condition themed area, individual research projects or individual researchers.

Donate to our CaRE Program!

All donations of \$2 or more are tax deductible.



[Read the paper](#)

A look at the Telehealth experience

CaRE researcher Dr Gabriella Tikellis recently published a paper about the Telehealth experiences of people with interstitial lung disease during COVID.

"The COVID-19 pandemic resulted in a rapid transformation of health services. This study aimed to understand the telehealth experiences of people with interstitial lung disease (ILD), to inform future service delivery."

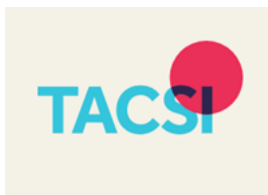
"Whilst there was a general satisfaction with the level of care received, the health care experience for those experiencing deteriorating symptoms was less satisfying, with Telehealth not always meeting their needs."

Noteworthy items from the sector...



World-leading Monash team produces its first [FODMAP cookbook](#).

The expert team that developed the world's first low FODMAP diet for people with irritable bowel syndrome (IBS) has produced a cookbook with delicious recipes and diet tips.



Unpacking co-design

In Australia today, 'co-design' has become almost interchangeable with 'consultation'. However, the concept of co-design and the range of design based traditions that sit under the co-design banner have something very important to bring to place-based social innovation.

[Read this article from TACSI to learn more about their take on genuine co-design.](#)



**Patient Engagement
Synapse**

[Fair Patient Engagement Planner.](#) Check out this co-created tool led by Synapse designed to:

- facilitate good practices in defining patient engagements
- empower open and transparent dialogue on fair remuneration for patient engagement activities between the patient community and the pharmaceutical industry.

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the team!



Together we can work towards improved medical outcomes.

Ange and the CARE Committee

CARE Program, Central Clinical School

Faculty of Medicine, Nursing and Health Sciences



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