



CENTRE FOR COMMUNITY-DRIVEN RESEARCH

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## Community project in Transthyretin Amyloid Cardiomyopathy: Information for the community

The Centre for Community-Driven Research (CCDR) is a non-profit organisation bringing much needed change and our vision is to facilitate meaningful connection between service providers, research organisations, the non-profit sector, practitioners, industry, government and the communities for which they provide a service or aim to benefit.

Patient Experience, Expectations & Knowledge (PEEK) is a research program developed by CCDR. PEEK studies give us a clear picture of what it is like to be a patient at a given point in time, and by asking patients about their expectations, PEEK studies give us a way forward to support patients with treatments, information and care. Some of the completed studies that we have done can be found at [www.cc-dr.org/peek/repository](http://www.cc-dr.org/peek/repository)

As you will see, these reports that are publicly and freely available are a great resource for stakeholders to use for future advocacy initiatives to demonstrate the experience, needs and preferences of their patient population, and to also use to inform future strategic plans to fill any gaps in services.

PEEK studies include an online questionnaire and a telephone interview with one of our nurses. This is what some participants in a previous PEEK studies have had to say about the experience:

"This is the first time anyone has truly taken the time to actually inform me, ask me and consider me since diagnosis - thank you!"

"Thank you for the opportunity to answer so many relevant questions. The questionnaire has raised quite a few questions in my mind, very helpful and constructive, some of which I plan to discuss with my GP and specialist. As a result...I feel better informed"

## Community project in Transthyretin Amyloid Cardiomyopathy

CCDR are embarking on a community project in Transthyretin Amyloid Cardiomyopathy including a PEEK study and a community forum. Anyone who has received a diagnosis will be welcome to participate in this study and we will aim to have a range of participants with various sub-types of Transthyretin Amyloid Cardiomyopathy – everyone is welcome to participate. Arms-length sponsorship has been received for this work from Pfizer Australia however the sponsor has no input into the design or implementation of this initiative. This is a condition of any funding that CCDR receives so that the research and projects that we do remains independent.

When we have finished the study we will hold a community forum with the single aim of giving patients and their families the platform to talk about their experience with those that make decisions about the type of treatment, care and information that they can access. The only outcome of the day that we aim for is that, when decision-makers go back to their offices and committees etc., they think about how their decisions may impact patients and their families and consider what is valued by the community when making decisions.

The general format that we have used in the past is to hold a morning session for patients and their carers only. This time can be used to run educational workshops or provide updates on research etc. (9.30am to 12.00pm). After breaking for lunch (12.00pm to 1.00pm) we then usually run an afternoon session (1.00pm to 2.30pm) where we invite external stakeholders (politicians, government, researchers, clinicians etc.) to meet with and listen to the patients about their experience and expectations of the future.

The timing of the community forum will be early November 2019 and we will see where most people are located to determine where the forum will be held.

## How to get involved

To register or for more information go to [www.cc-dr.org/peek/register/](http://www.cc-dr.org/peek/register/) or contact Ms Ishka Bless at [ibless@cc-dr.org](mailto:ibless@cc-dr.org) or via telephone at 0422 971 493