

How to share your PKU story with media

A guide to engaging with local media



How to find your local media

- The Australian media landscape has drastically changed over the past several years, with much fewer outlets operating in, or covering, local and regional news.
- For example, in 2020 as a result of COVID-19, News Corp (one of Australia's largest media organisations) announced that 112 of its suburban and regional newspapers would no longer be printed, with 36 closing altogether, and 76 remaining as online publications only.
- With so many changes taking place, it's difficult to keep track of all the media outlets that are still operating.
- As a starting point, you can visit the Communities in Control 'Media Contacts' page, via the following link: <https://communitiesincontrol.com.au/take-control/media-contacts>, where you can find a list of all media in your state, along with their contact details (see below screen grab for how to access these lists).
- While some of these lists haven't been updated since late 2020, they include the website details of all publications, so you can easily access up-to-date information on each media outlet.

The screenshot shows a web browser window with the URL communitiesincontrol.com.au/take-control/media-contacts. The page header includes logos for 'Communities in Control' and 'INSTITUTE OF COMMUNITY DIRECTORS AUSTRALIA'. A navigation menu contains links for 'About', 'Conference', 'Speakers', 'Speeches', 'Performers', 'Joan Kirner Oration', 'Take Control', 'Partners and Exhibitors', and 'Register'. A large blue banner reads 'Media contacts'. Below the banner, a red arrow points to the URL. The main content area has a heading 'Click on your State or Territory below to download contact details for many of the newspapers, radio and television stations operating in your area.' Below this is a list of Australian states and territories: Australian Capital Territory, New South Wales, Northern Territory, Queensland, South Australia, Tasmania, Victoria, and Western Australia. A red box highlights this list, and a red arrow points from a text box to it. The text box says: 'Click on the state where you live. An excel spreadsheet will then open on your screen with a list of details for regional, suburban and state-based media outlets in your area – across print, online, radio, and television'. Below the list, there is another heading: 'Utilising the media is useful for communicating any news, stories or information you want to get out to the public. Use the lists below to find basic contact details for many of the newspapers, radio and television stations operating in your area.' At the bottom, a paragraph reads: 'Remember, it is not just the media outlets in your geographic area you need to target. Look at also targeting all those specialist media outlets that cover your area of interest - multicultural media, disability media, etc.'

Engaging with local media

- Remember and review your story – this is what you will be telling the journalist or reporter.
- Using the contact details for the media outlet that is in (or near) your area, call and ask to speak with someone who would be interested in a local story on a health issue.
- Tell the journalist/reporter your PKU story – remember, this is your own personal experience and no one else can tell it except you. This will help you make an emotional connection with the journalist/reporter you speak with.
- The journalist/reporter will likely ask you a few questions about PKU, the main issues you are raising, or your personal story. They may even ask to call you back at another time, if they are in the middle of another story – be open and honest with them about what your concerns are, and your availability to speak with them.
- Remember to focus on the key points you want to convey, and your personal experiences and real-life examples you want to share.

Talking to media

The below questions may help you to prepare for sharing your experience with local media:

- Tell me about yourself/child/partner/sibling/family member/friend with PKU?
- When were you/they diagnosed?
- How did you/they first notice they was something not quite right?
- When did you decide to do something about it (e.g. see a doctor, get a second opinion, etc)? What was the process?
- What happened at the time of diagnosis?
- Did you know anything about PKU before you/your loved one was diagnosed with the condition?
- What was your/their recommended course of treatment?
- How have you/they managed their PKU over time, and what differences have you/they noticed when Phe control was (or wasn't) maintained?
- How would you explain the PKU diet to someone? What do you/they find most challenging about it?

Questions to expect when speaking with a journalist/the media

- Who else can support your story (e.g. family, friends, doctor/s)?
- Are you (and your family) willing to be photographed?
- How has PKU impacted your/their life?
- What needs to change/what are you asking for – and why?
- What is the most important piece of advice you would give to other people diagnosed with PKU, and their families, friends or carers?
- What do you want the general public to know about PKU?

Handling media interview questions

Remember, an interview is not a test of your ability to answer questions. Rather, it is an opportunity to convey your own personal point of view. Below are some tips to consider when engaging with media.

Do:

- Remain focused, concise and alert.
- Reference your issue and reinforce the main impacts living with PKU has had on your/your family's/your loved ones' life.
- Start with your conclusion first (i.e. what you want) and be clear and transparent about your personal experiences.
 - For example, you may wish to start by speaking about the unmet medical need that exists for Australian adults with PKU, and the importance of the Government providing subsidised access to medicines for rare diseases.
- Rephrase or repeat the question if you need a moment to think (e.g. *"what I really want to say is..."*).

Don't:

- Respond instantly to an interview request, unless you are completely ready. You can always call the journalist back when you are in the right space and time to discuss the issue.
- Talk beyond your knowledge or your own personal experiences as a person living with PKU, or a family member/friend/carer of someone living with PKU. You are not expected to be an expert on the disease or treatments.
- Speculate or speak for others.
- Repeat controversial words or phrases.
- Be embarrassed to say *"I don't know..."*.
- Never say *"no comment"*! Being open and transparent with the journalist will allow you to form a connection with them, and encourage them to support your cause and advocate for your issues.

Questions on the price of medicines

- Remember – you are not expected to be an expert on PKU or its treatments, or on the political and medicines reimbursement systems.
- If the journalist wants this information, they can contact a doctor who specialises in PKU, the company that makes the treatment, or someone from the Government, directly.
- If you are asked about the price of prescription medicines for PKU, you may wish to consider one of the following responses:
 - *"It's important for the Australian Government to fund the latest PKU treatments as they become available, to make it affordable for patients and their families."*
 - *"If the Australian Government doesn't make this new treatment available on the Pharmaceutical Benefits Scheme (PBS), no patient or family with PKU will be able to afford it."*
 - *"Adults with PKU currently don't have subsidised access to any prescription medicines to treat the condition – medicines which are already available to adults with PKU around the world."*