

CIICA Live, JULY 2021: CI Advocacy: how do we do it? Advocacy and no budget?

Summary of the key messages from the event:

We heard about some amazing examples of advocacy by patient groups from around the world. A key theme summarised by Holly Teagle was Think Global, Act Local See Holly's summary at [CIICA LIVE in JULY: CI Advocacy: how do we do it? – CIICA \(ciicanet.org\)](https://www.ciicanet.org/ciicanet-live-in-july-ci-advocacy-how-do-we-do-it/)

Here are some of the key messages from the presentations and suggestions for future activities. You can see all the individual examples at www.ciicanet.org/events

The evidence we refer to can be accessed here www.ciicanet.org/resources

Key points for Advocacy

1. WHY Advocacy?

- We need to be really clear what the problem is we are addressing. CIICA's analyses of the problems we are trying to address through advocacy are at: [Why CIICA? – CIICA \(ciicanet.org\)](https://www.ciicanet.org/why-ciica/)
- CIICA wants to address the gap between those who could benefit and those who receive Cochlear Implants, followed by better support and aftercare for those who have CI's.

2. HOW do we do this globally and within individual countries?

- Develop greater awareness amongst politicians, audiology and the public about the benefits of CI. For more advice about how to advocate with politicians see; <https://www.ciicanet.org/wp-content/uploads/2021/07/Anita-Grover-CIICA-LIVE-July-2021.pdf>
- Provide good, clear evidence of the benefits of CI on health and wellbeing through improved communication. WHO World Report on Hearing comments that CI "is one of the most successful of all neural prostheses" see summary of WHO evidence at www.ciicane.org/resources
- Use the evidence of the cost effectiveness of investing in CI to reduce the cost of hearing loss and the burden on other health and social care services. Use the Spend2Save evidence and message at; <https://www.ciicanet.org/resources/spend2save/>
- Improve the support for advocates, ensuring that people who have or need a CI have the support, information and evidence to be effective advocates locally
- Work together with common messages at national level and globally
- Provide advocacy groups with the tools for change they need to do this
- Be positive and non-confrontational!

- Avoid jargon and overuse of medical language and terms

3. **Working Together.** The importance of patient groups and advocates working together and learning from each other to raise awareness and standards across countries and using this to benchmark against other countries. CIICA was seen as crucial to support this - Think Global, Act Local was a key theme from a number of speakers.

4. **Good Communication.** Ensure good communication that focusses on people's values – their right to good communication and support. We need to ensure we lead with the vision and change we want to make: CI's will provide better communication and therefore improve lives, health and wellbeing before we use the facts around the cost benefit to society.

5. **Evidence.** Use all the evidence that is available. There is a huge amount of good evidence including the WHO report on Hearing Loss, Spend to Save, and international standards such as the consensus statements. You can find all of these here; <https://ciicanet.org/resources/>

6. **No budget?** There is a lot that can be done with little budget if you harness the opportunities of social media and be innovative.

7. **Perseverance** in advocacy is crucial as we learnt from New Zealand. Don't give up, or be put off by an apparent lack of interest – keep going!

What next?

It was agreed that to help improve the profile of the issue that CIICA would produce a template press statement to support the briefing materials that people could use in their own countries.

Actions:

CIICA is to produce a summary press release which can be adapted for difference contexts but which will give the common messages.

Volunteer groups are translating the summaries of the WHO World Report CI evidence to use with the press release.

Thanks to all of those who shared their brilliant examples with us.

Do you want to share yours please send them to CIICA for our website: info@ciicanet.org