



EUROCIU
EUROPEAN ASSOCIATION OF COCHLEAR IMPLANT USERS

The importance of CI advocacy


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Question

At the current pace, how long would it take to implant everyone who would benefit from implants right now?

Think about this for a couple of minutes!



What is advocacy?

- Actively supporting a cause.
- Usually stems from dissatisfaction.
- Success depends on the strength and effectiveness of advocacy.




Who can advocate?

- CI users (by default).
- CI users and their families.
- CI associations.

Then:


- Politicians, health ministers etc.



Who cannot advocate?*

- Those who profit financially, for example:
 - CI manufacturers.
 - Private CI clinics.
- Others:
 - Researchers
 - Doctors

* They can try to advocate but they face obstacles.



Intentional antagonists

Some parties work against CI advocacy.

- Some culturally deaf.
- Some deaf media streams.
- Some private hearing aid dispensers.



Accidental antagonists

Sometimes we advocate against ourselves.


- “Bad” outcomes carry undue weight.
- Even with the best outcomes, any negative comments are seized upon.
- Talk about “cochlear implants” not about “a cochlear implant”. 
- We obstruct ourselves with internal politics.



Question

At the current pace, how long would it take to implant everyone who would benefit from implants right now?

What do you think?



Answer?*

In 30 years, ~1 million people have received implants, ~250,000 in Europe.


19 out of 20 CI candidates do not have implants.

The number of people needing implants is rising faster than implantations.

$30 \times 19 = 570 \text{ years}$

570 years is a death sentence, not a waiting list!


*If you do not agree with my figures, use your own!



Why is advocacy needed?

- Access: To reduce 570 years to an acceptable timeframe. 10 years perhaps?
- Awareness: People need to be aware of CI.
- Lifelong care: We will need 100 years of care after the very last child receives a CI.


In the past, advocacy has been too slow and ineffective. We need to work much harder!



The cost of implantation

- Implants cost nothing!
- They are a 10:1 investment
- If a country can afford NOT to implant, it can afford to implant.

Governments and health services must stop making feeble excuses and seize the investment opportunity!



Who do we need to advocate to?

- Health ministers
- Governments
- Hospitals
- Medical professionals
- General public
- Potential CI candidates
- Social services
- Schools
- Employers
- Implant manufacturers...



What is your association doing for advocacy?

Associations serve two key functions:

- Community
- Advocacy

Does your association do meaningful advocacy work?

Do you set and follow advocacy targets, lobby politicians or take matters to court?

If not, who does?



Isn't advocacy EURO-CIU's job?

In EURO-CIU we can:

- Support each other in our advocacy efforts.
- Raise awareness at a European/global level as a single voice.

BUT: hearing care decisions are ultimately made locally.


"What can EURO-CIU do for us?"

"What can we do for EURO-CIU?"



How does EURO-CIU work?

- 5 board members: President, two Vice-Presidents, Treasurer and Secretary.
- All CI users or parents of CI users.
- Elected for terms of 4 years (max. 2 terms in same role).
- We are voluntary. We work in our own time, unpaid.



2023 EURO-CIU elections


In 2023 we will elect, at least:

- President
- 1st Vice-President
- Treasurer

Will you stand for one of these roles?

Identify candidates in your associations.


Half of our member countries have not had a member on the board; you can change that.



What can we do as advocates?

Big steps are made up of small steps:

- Inform your members about EURO-CIU.
- Sign your members up to our free newsletter.
- Add our logo and link to your websites.
- Participate in surveys and data gathering.
- Use the advocacy resources, for example of EURO-CIU and CIICA.
- Contribute to the EURO-CIU newsletter.
- Take more interest in what EURO-CIU and your own associations are doing.




Young advocates

Why are young adult CI users underrepresented?

It seems to me:

- They are not being properly prepared to advocate for themselves.
- They are doing so well with CI so far that they are not angry enough.
- We need to instil in young CI users a sense of social responsibility to help others, just like them, to enjoy the benefits of CI.




The end of CI advocacy

There is no end...

- We will never reach a utopia situation where every problem is solved.
- The challenges will evolve.
- CI advocacy will be needed until the last CI recipient dies.

We must advocate more strongly for CI kids, parents of CI kids, and CI adults.


Identify your goals, work to them, and celebrate every big or small success!



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Thank you for listening!

- Any questions?
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