Nothing about us without us

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Steering Committee, World Hearing Forum, WHO

ESPCI 2025

CIICA

Nothing about us without us…

- Governments and decision makers listen to users, families, patients….. real people. These groups are really important and effective : so…
- **Tanya Saunders,** CI-parent and Founder, AVID Language - books for children with hearing loss: Slow progress without parents
- **Tobias Fischer,** EURO-CIU: Advocating for myself from childhood to adulthood
- **Elmar Haake** : German self-help groups within DCIG - Why?
- **Roswither Rother:** HCIG: Self Help and Clinics: a good cooperation for everyone
- **Harald Seidler,** Deutscher Horverband :Speaking with one voice: our German developments
- **Sue Archbold**: **CIICA:** A global advocacy network

Slow progress without parents

Spot the gap!

Two things everyone in this room knows to be true:

1) Raising a deaf child to listen and speak requires a team effort but **parental involvement is the single most important factor in securing a successful outcome.**
2) Over 90% of deaf children are born to hearing parents with **no history or experience of hearing loss** in the family.

So… How can you, as professionals, support parents to make this necessary transition?

From a position of little or no knowledge of hearing loss
(and resulting low confidence in their own ability to parent)

↓

To becoming their deaf child's strongest advocate and team leader
(as they would automatically be for a hearing child)

My daughter, Onna, and I at her CI-activation

Slow progress without parents

- **To secure more consistently successful outcomes for deaf children, parents need to be empowered from the first moment of their child's diagnosis.**
- **Language and body language** are all-important in communication with parents - especially when first informing them their child is deaf. ***Avoid any "expression of deficit"!***
- Medical diagnoses differ, but wherever possible convey **a spirit of aspiration.** If you, as professionals, can instil self-belief in the parents, they will instil self-belief in their children... and a lot of grit and self-belief is needed on this journey!
- Parents need time (and permission!) to process emotions (grief, anger, shock) but also need to hear that **THEY can make an all-important difference to their child's future.**
- **Don't overwhelm parents with information at diagnosis.** In the first instance, parents don't want info - **they want HOPE.** They get this from other parents:
    - **parent mentor networks**
    - **"lived experience" accounts in books & blogs** (eg. "Voices of Hope" by Estelle Gerrett; "How Do You Deaf?" by Kerry Tidman; CIICA website)
    - **social media** (signpost safe, objective online spaces, eg. the Facebook group, "Parents of Children with Cochlear Implants")
- After a few weeks, **parents will come back to professionals for information** and to seek a way forward. Now you can load them up with info!
- **Try to give parents options.** Don't "box them in" or make them feel like their child is a "commercial opportunity" (an assertion often made by the anti-CI lobby).

different not less

~~I'm sorry...~~

"It's a different situation to what you expected, but there is so much you can do to ensure your child thrives... same dreams, different strategy to get there."

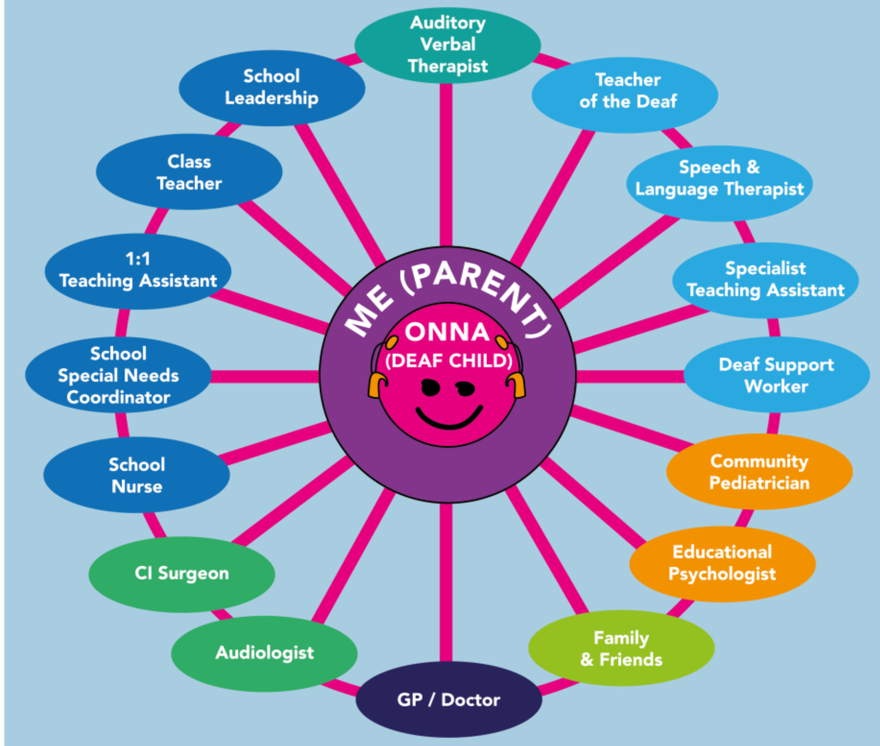
"You have options. We'll support you with all the information you need to help you choose what's best for your child and your family..."

Slow progress without parents

- **A successful team effort requires parents listening to professionals, but also professionals listening to the parents.**
- If parents feel powerless, with their insights and instincts ignored by "the system", the end result is less successful outcomes for children.
- As far as possible, **care plans should be individualised** to maximise the positive impact of parental involvement, taking into account a multitude of factors that can vary from family to family, including (*inter alia*):
  - **Logistical, practical and financial realities, including family situation**
  - **Parents' state of mind** (do they need support to come to terms with the diagnosis, and process all the decisions they need to make?)
  - **Family's cultural norms and expectations**
  - **Family's values and aspirations**
  - **Is there an open, collaborative approach and regular communication between all "team members"?**
- **At the end of the day, parents just want to be parents, with control over the big decisions affecting their family's future.** Parents will trust and value the advice, skills and intervention provided by the diverse team of professionals involved in their child's journey, providing those professionals recognise the parents' vital role too... and in this atmosphere of mutual trust, respect and collaboration, **the winners will always be the children.**

As a parent, becoming your child's "team leader" can feel daunting at first, but remember: No-one else knows your child as well as you do.

"TEAM ONNA" (my daughter)



ME (PARENT)
ONNA (DEAF CHILD)

Auditory Verbal Therapist
Teacher of the Deaf
Speech & Language Therapist
Specialist Teaching Assistant
Deaf Support Worker
Community Pediatrician
Educational Psychologist
Family & Friends
GP / Doctor
Audiologist
CI Surgeon
School Nurse
School Special Needs Coordinator
1:1 Teaching Assistant
Class Teacher
School Leadership

[Some children will also require supplementary specialist intervention for additional needs, and some parents will require counseling or therapy support]

Nothing about us without us..

Advocating for myself from childhood to adulthood

Tobias Fischer, M.Sc.

EURO CIU
EUROPEAN ASSOCIATION OF COCHLEAR IMPLANT USERS a.s.b.l.

The Beginning of My CI Journey

Early support through the Early intervention group in Friedberg (now CIC Rhein-Main).

Continued support even after my first CI surgery.

Follow-up treatment at the newly founded CIC Hannover by Dr. Bodo Bertram.

Challenges in My Youth

During school years: almost no contact with other CI users.

Weekly support by a teacher from a school for the hearing impaired

After getting my driver’s license and turning 18, I start meeting others.

A new self-help group was founded in Marburg – CI SHG Mittelhessen.

This exchange helped me decide to get a second (bilateral) CI.

Engaging with Young CI Users

- In 2007, I received my second cochlear implant.
- I founded the first CI youth group – CI-JuGru-Mittelhessen.
- Connecting with peers was a key experience for self-confidence and empowerment.

Starting Over in a New Country

After moving to Austria, I encountered a different CI care system.

I had many questions – especially about follow-up care abroad.

There was a local group, but it lacked visibility and openness to my input.

Today: Supporting Others, Empowering Myself

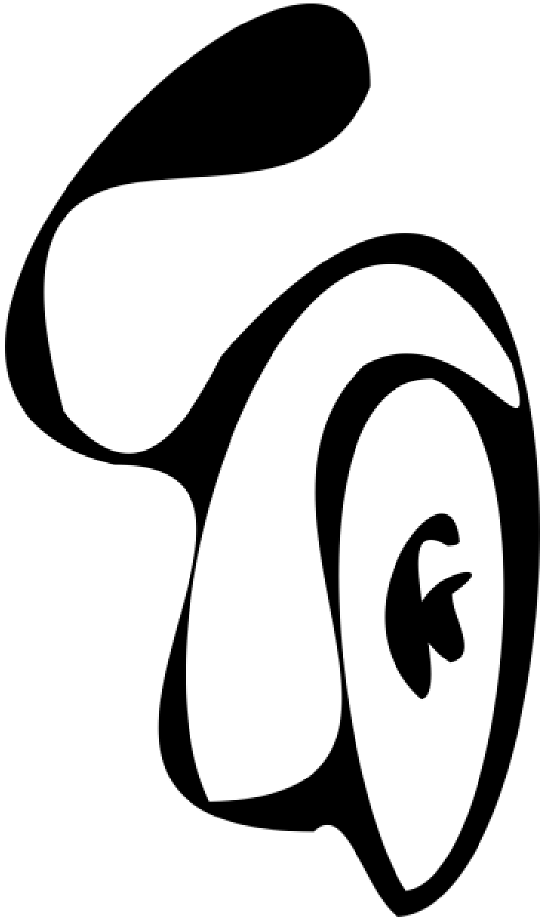
Since 2017: active member of the Austrian CI organization ÖCIG.

Since 2019: active Cochlear Mentor.

I support CI users in many ways – from device questions to emotional support.

Peer exchange continues to be the most important part of my journey.

Contact



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- https://www.oecig.at
- https://eurociu.eu/

Deutsche Cochlea Implantat
Gesellschaft e.V.

- Self-Help Groups within DCIG -

Why do we need them ?

Elmar Haake, member of the DCIG-board

Self-help groups have become the fourth important pillar of our healthcare system, alongside outpatient, inpatient and rehabilitative care.

KV North-rhine

WHO: „Health: Complete well-being“

Social

Mental

Physical

Health…?

CI-Surgery

Medicinal Aftercare

Hearing

Understanding

Therapist: That’s brilliant,
You’re understanding so well! (… 80 % one syllable words)

CI-User: But yesterday at the birthday party I didn't understand anything at all

Confrontation with myself

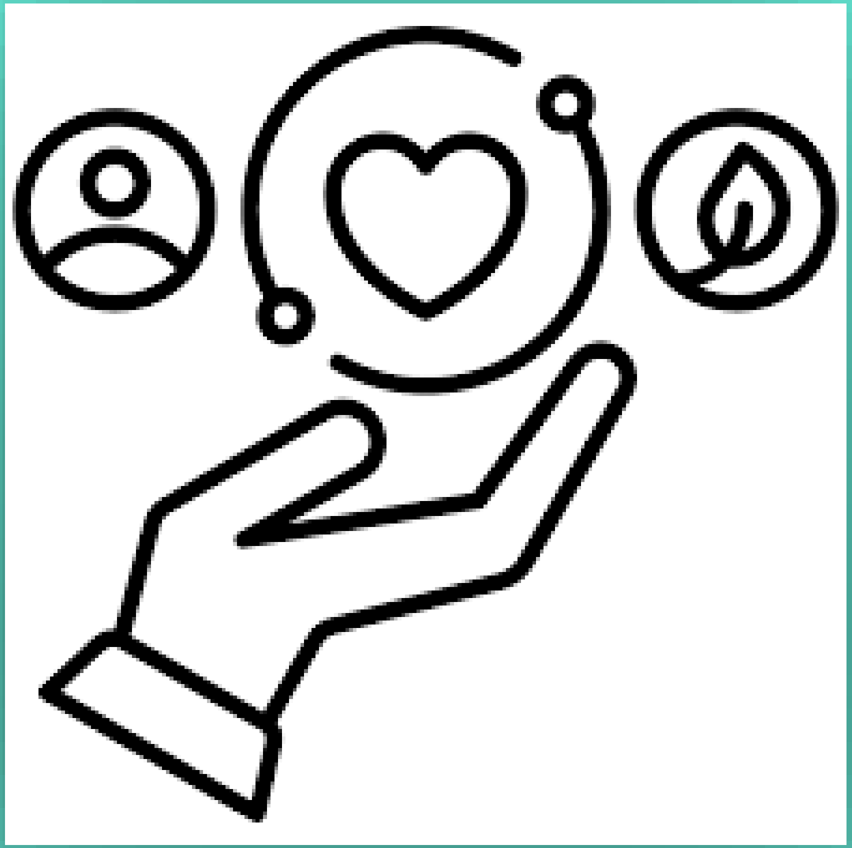
Hearing/Understanding with CI „in life“

- Training

Failing

- Training

→ **Group meetings**
→ **Weekend-Seminars**
→ **Personal contacts**
→ **Important note: Emotional acceptance in the decision-making process for a CI for CI candidates by exchange with CI-Users**



Seminars, joint exchange

I’m not alone

I can work on my attitude

DeafOhrAlive – Young self-help groups

„For me, DeafOhrAlive means no longer being an outsider, but now being in the centre of a party full of hearing-impaired people

Community experience … that's great!"

DeafOhrAlive – Young self-help groups

„I meet other hearing-impaired people at the youth camps and realise that I'm not alone in my situation.

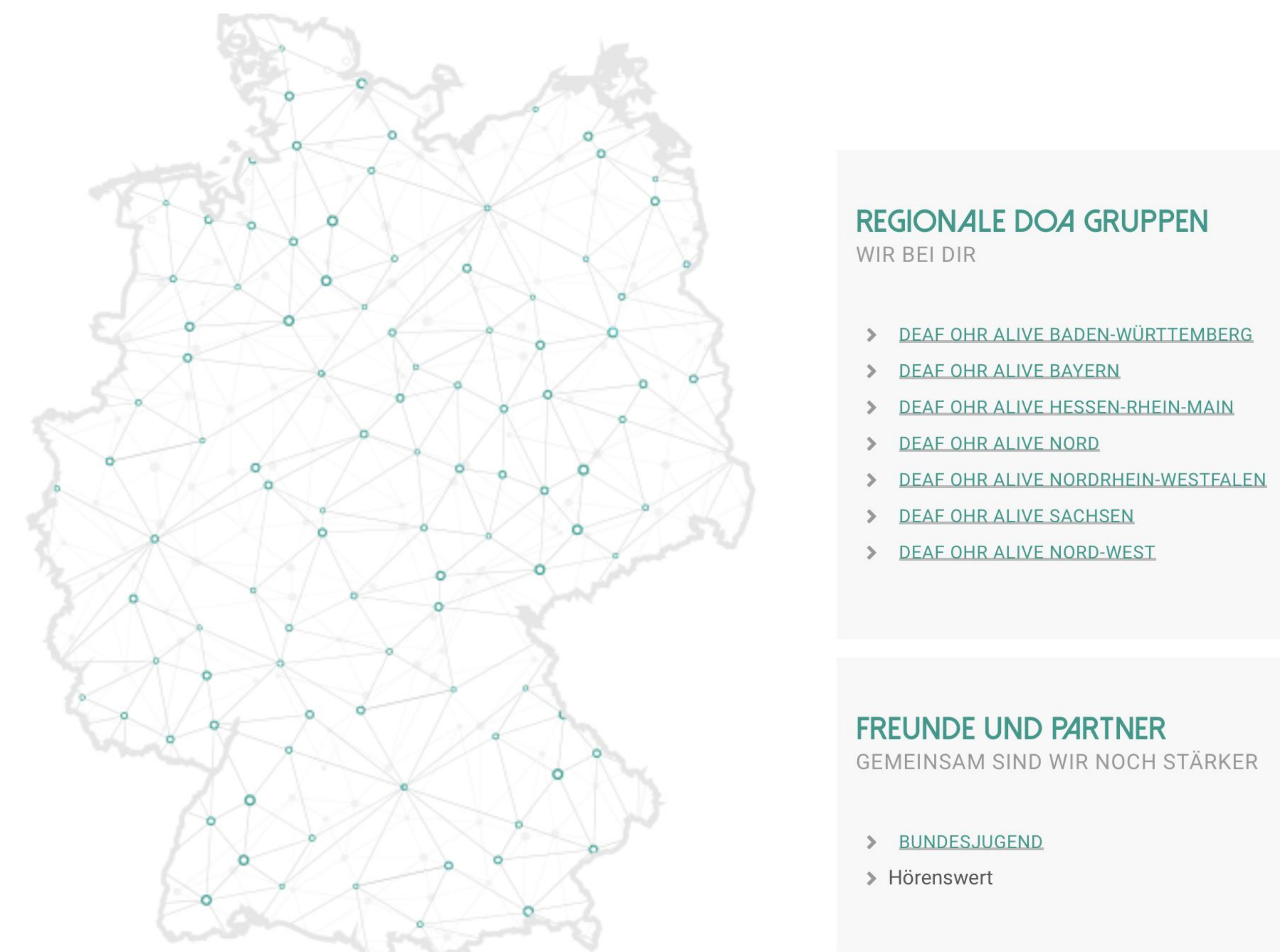
It gave me a lot of courage for school and beyond.

“

➔Contacts with other pupils

➔exchange, tips, technology

DeafOhrAlive – Young self-help groups



REGIONALE DOA GRUPPEN

WIR BEI DIR

- DEAF OHR ALIVE BADEN-WÜRTTEMBERG
- DEAF OHR ALIVE BAYERN
- DEAF OHR ALIVE HESSEN-RHEIN-MAIN
- DEAF OHR ALIVE NORD
- DEAF OHR ALIVE NORDRHEIN-WESTFALEN
- DEAF OHR ALIVE SACHSEN
- DEAF OHR ALIVE NORD-WEST

FREUNDE UND PARTNER

GEMEINSAM SIND WIR NOCH STÄRKER

- BUNDESJUGEND
- Hörenswert

Partner workshops – mutual understanding

Therapist:

„We immediately recognise the patients who are in self-help groups.
We can work much better with them - in a more targeted way.“

Therapy

Breaks

Games

Restaurants

Pubs

Peers are important ‘therapists’ in everyday rehab life

Self-help groups offer ways to feel healthy

– Self-help groups –

An important partner for a successful aftercare, according to the WHO definition they are essential

– Self-help groups –

Because life is not
an one syllable word

SCAN ME

-> Link zu den Selbsthilfegruppen in Deutschland

Hannoversche
Cochlea-Implantat-
Gesellschaft e. V.

Without us it doesn't work

The role of self-help in CI care

Hannoversche Cochlea-Implant Gesellschaft (HCIG)

Hannoversche
Cochlea-Implantat-
Gesellschaft e. V.

The Hannoversche Cochlea-Implant-Gesellschaft e.V. (Hannover Cochlear Implant Society) was founded at the Hannover Medical School in 1996 and currently has over 500 members.


CLARION

What did we do in the HCIG

Hannoversche
Cochlea-Implantat-
Gesellschaft e. V.

Sharing experiences and mutual support
Information and support for those affected by similar issues
Public relations and advocacy
Group community and socializing
Knowledge acquisition and collaborative learning
Networking and cooperation

Our location at the DHZ is very important for our collaborations.

The proximity to physicians, engineers, educators, and researchers enables us to exchange information, collaborate on joint projects, participate in research, and provide expert support where lay knowledge ends.

Collaboration also involves self-help acting as a corrective.

This includes critical feedback for the benefit of patients, but also mutual support.

Positive effects of self-help

We receive positive feedback that self-help is often perceived as very helpful.
At seminars and discussions, participants learn more about their hearing loss and learn how to cope with it better.
They often feel better understood, accepted, less isolated, and learn to handle their CI more confidently.

This increases their courage and quality of life.

What we want for the future

Hannoversche
Cochlea-Implantat-
Gesellschaft e. V.

- Individualization instead of standardization
- Transparency and information regarding pre-operative care
- More information about rehabilitation, technology, more time for programming, and consultation

The current board of the HCIG

Thank you for your attention

Nothing about us without us

DHV introduces itself!

1. Question

- Can you **hear** me ?
- Can you also **understand** me?

- **We want to be heard !**

Significance for Germany

DHV
Deutscher
Hörverband

33%

of people living with untreated hearing loss are at higher risk of lose their independence and suffer from secondary diseases!

DHV
Deutscher
Hörverband

Significance for Germany

5.8 MILLION

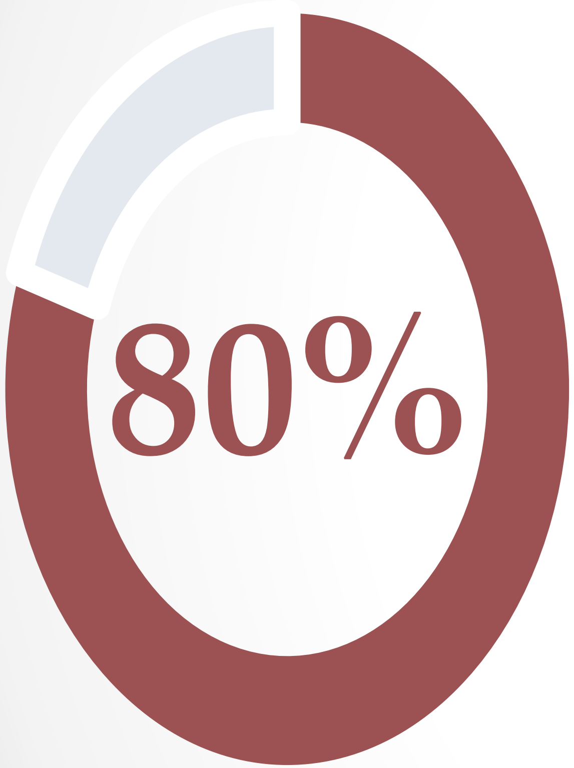
People in Germany live with severely debilitating hearing loss

3,8

MILLION

are untreated by it!

Significance for Germany



of Germans with severe to profound hearing loss have never been informed about alternative hearing solutions!

Bedeutung für Deutschland

39

BILLION €

annual costs due to untreated hearing loss!

DHV
Deutscher
Hörverband

DSB
Hören · Verstehen · Engagieren

Deutsche Cochlea Implantat
Gesellschaft e.V.

- Founded 10.12.2022 in Frankfurt/Main
- Umbrella organization members: 15 state, regional and federal associations
- 14 million hearing-impaired people in Germany
- 4 million hearing aid users 50 000 CI wearers

Our goals:

- Improving the situation of the hearing impaired
- Removing hearing barriers
- Closing gaps in care

- **Strength** is only possible in the bundling of forces
- **Communication** could be improved
- **Online format** has become a matter of course
- Finding **common goals** means focusing on activities that help everyone
- Letting go of some of your own projects to **increase effectiveness**

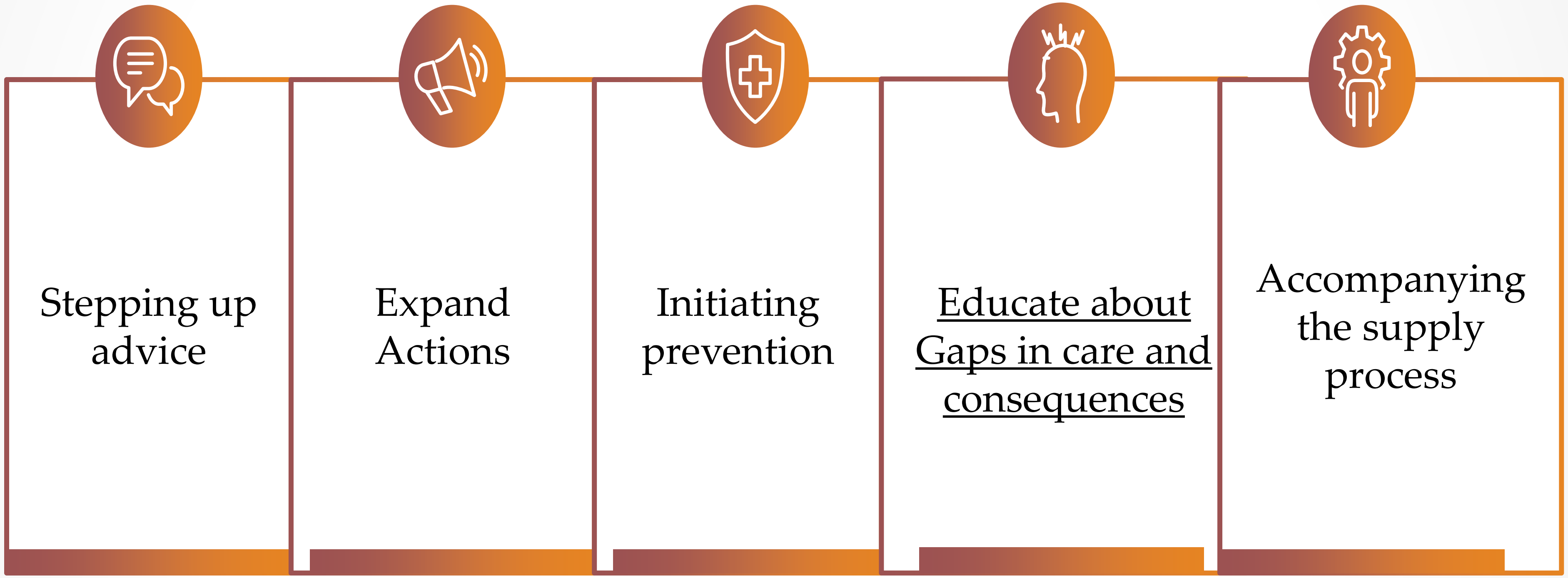
Visibility

-
- **Political talks** with government
- **Press**
- Talks with **acousticians BIHA**
- Discussions with **CI companies**
- Discussions with **service providers**
- **ENT**

- **Solidarity**
- We **support each other** with advice, knowledge, events, committees, problems
- We **pool our resources**
- We have good ideas and **use them together**
- **No one is left alone**

- **Effectiveness**
- We **don't do anything twice**
- We can form **more project groups**
- Make good promotions available (e.g. online)
- **No long-term offices**, but **temporary project participants**

OUR MISSION:



Stepping up advice

Expand Actions

Initiating prevention

Educate about Gaps in care and consequences

Accompanying the supply process

INFORMATION FOR ADVOCACY NEEDS TO BE CLEAR….AND GROUNDED IN REALITY

- **CIICA**, A global **network now** reaching 74 countries,
- 670 individuals, 120 organisations working
  - To address access to CI and sustainable lifelong services
  - To provide advocacy groups with the tools for change they need
  - To inspire each other to action

  - ***No Awareness,***
  - ***No Information,***
  - ***No Demand,***
  - ***No Service** (Carolina Der, CIICA Conversation, 2025)*

- www.ciicanet.org

CIICA

Join CIICA to advocate for lifelong CI services

CI Advocacy in Action 2024 Brussels:

A different sort of conference...

Led to collaborative action

CI Advocacy in Action 2025

Advocating for sustainable CI services

Go to www.ciicanet.org

50% reduction for CI users before 30 June

CI ADVOCACY IN ACTION 2025

Advocating for increased access to cochlear implantation and lifelong sustainable services

OCTOBER 16/17, 2025
BRUSSELS, BELGIUM

FURTHER INFORMATION AT
WWW.CIICANET.ORG

REGISTER HERE
TO BE PART OF ACTION!