

NETWORK MEMBERS: CONNECT WITH CIICA



Who are we? The Foundation of CIICA

The issue addressed by CIICA is the massive gap between those who could potentially benefit from CIs and those who have them: only 5-10% of those in developed nations with severe to profound deafness and hearing loss have a CI, in spite of the benefits to individual and society being well proven, including the cost effectiveness. The proposal for CIICA to address this issue globally followed an international consultation with key stakeholders about the role of CI advocacy work and its strengths and challenges. This consultation arose from the agreements and interest expressed at a meeting of the Consumer and Professional Advisory Committee (CAPAC) including all industry stakeholders in Geneva in December 2019, where the International Consensus Statements on adult cochlear implantation (CI) were presented. COVID 19 has clearly impacted on funding and practices for CI services worldwide and the potential for CIICA has become even more important and timely.

CIICA provides an opportunity for a new way of working for CI advocacy groups, bringing them together with opportunities for sharing and collaboration to strengthen the user, including children and young people, and family voice. Here is our vision, goals and plans and objectives in achieving our impact, driven by the user and family voice. Network Members will be those who support these plans and who wish to be part of the Community.

Our Vision for CIICA

The vision of CIICA is a world in which awareness of the benefits of CI are well known to those with deafness and hearing loss, their families, professionals in the field of deafness and hearing loss, the general public and public health decision makers. A world where access to CI and lifelong support is available for all appropriate.

Our Goals for CIICA

To increase the number of people globally who have access to cochlear implants and lifelong aftercare by:

- Raising the international global awareness of the health, social and economic benefits of cochlear implants for those who could benefit from implantation, health care practitioners and wider society.
- Empowering user led advocacy and awareness raising activity to influence governments and health funders to invest in addressing the under provision of CIs and other implantable technologies, related habilitation, after care and up-grades.
- Supporting CI advocates with the tools they need to achieve change.

Our Impact

The impact will be improved access globally to cochlear implantation, rehabilitation, life-long technical support including processor upgrades and aftercare driven by CI user advocacy initiatives.

How we will achieve this: our agreed objectives

- To share user and family driven advocacy via a shared digital platform: the Community of Action.
- To empower CI user groups globally
- To increase awareness of the benefits of CI
- To increase referrals for CI and access
- To foster collaboration across the CI sector
- To enhance the global impact of user advocacy on CIs
- To influence public policy decisions on hearing health and CI
- To improve lifelong care for those with CI
- To provide an opportunity for data collection, and user driven research on CIs
- Develop and support advocates to become regional and global leaders in their community and have greater impact internationally.
- To exchange resources and research updates

How we will work together: our values

- Independent
- Sharing
- Empowering
- Diverse
- Transparent
- Collaborative
- Inclusive
- Promoting Trust
- Accessible

We will:

- Maintain a professional and a respectful relationship with all community members
- Value the activities of other members
- Give advice and support to the Chair and Co-ordinator and Steering Group in achieving the aims of CIICA
- Work with honesty, transparency and integrity at all times, ensuring that a consensus approach is maintained to achieve the aims of CIICA
- Try to achieve consensus where possible and respect people's and organisations' views where this is not possible
- Keep the overarching goals in mind, while recognising different priorities in different places and systems and valuing diversity
- Be willing to share resources and collaborate to achieve the aims of CIICA: to obtain permission before using another's work and always to acknowledge others' work.

Network Members will include:

- Voluntary organisations and groups and individuals involved in advocacy work
- Patient, Family and Industry Advocacy Groups and individuals
- Professional organisations involved in CI and hearing loss
- Policy groups and institutions related to hearing loss
- Academic institutions with links to policy work
- International agencies with an interest in hearing loss
- Governments and funding decision makers