

INCA Research Committee

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8th INCA Summit, Virtual Format

2 April 2020



Strategic imperative 2: Advance research on NETs

Strategic goals by the end of 2018 INCA will:

- Be providing patient-friendly information about ongoing NET research on the INCA website
- Have secured consensus from key stakeholders on the potential barriers to improving NET patient outcomes and research strategies that need to be deployed to advance NET research in the interest of patients

By the end of 2022 INCA will:

- Have a significant influence over and input into defining the global research agenda for NETs
- Ensure that NET patients have a voice in the development of new diagnostics and therapies for NET
- Be the “go to” place for NET patients seeking information on clinical research and on-going clinical trials



Short Term – Long Term Goals

Short term actions

- Establish a clinical trial database for NET research and make this available on website
- Start to provide members with education on how patients can have a voice in the drug development process (eg. Webinar given by a Eupati graduate)
(website)
- Convene a multi-stakeholder scoping meeting to understand barriers in NET research and how to advance research in the interest of patients

Long term actions

Use different channels to provide patient friendly explanations about on-going clinical research on NETs

- Facilitate the establishment and support the organisation of a Multi-stakeholder Global NET Research Forum that will help drive the NET research agenda and push for research that will have the largest potential impact on transforming patient outcomes
- Develop a training programme for building NET patient capacity to contribute to the drug development process
- Leverage relations with pharmaceutical companies and key academic researchers to secure a patient voice in the development of new diagnostics and therapies for NET



Achievements to Date

- Website:

<https://incalliance.org/category/research/> updates of latest global research including clinical trials that are recruiting

- Facilitate the establishment and support the organisation of a Multi-stakeholder Global NET Research Forum that will help drive the NET research agenda and push for research that will have the largest potential impact on transforming patient outcomes

World NET Forum – delayed to 2021



Key Activities 2020

- **NET Patient Research Advocates**

Development of online learning modules for INCA members, topics to be finalised:

- Statistics and why they matter
 - The importance of Patient Reported Outcomes and Quality of Life
 - How medicines are development works – why patient engagement matters
 - Evidence based patient advocacy
 - Patient Advocacy in Action & Community Advisory Boards
 - Big Picture – how does it all come together from clinical to publication to HTA and access
- **Continual updates on website, greater focus on clinical trial awareness and recruitment**
 - Including lay summaries of current trials
 - Registry of global trial participants
 - Scientific / research papers



Next Steps

- Finalise topics for research advocate modules and receive final quote
- Assist in the development and dissemination
- Continual updates of website
- Engagement and partnership strategy to be developed with all medical societies and industry stakeholders (round table)
- Additional recruitment to Research committee

