

# INCA Boot Camp for Neuroendocrine Tumor (NET) Research Patient Advocates

## Advances Education and Patient Engagement in NET Research



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### PURPOSE

- The INCA Boot Camp for NET research patient advocates is a tool to build the capacity of NET patient advocates to actively contribute to the research process.
- The project has focused on building a community of educated patient advocates dedicated to driving patient engagement in NET research.

### BACKGROUND

- The International Neuroendocrine Cancer Alliance (INCA) is an umbrella organization representing 27 neuroendocrine tumor (NET) patient advocacy and research organizations across 6 continents.
- One of INCA's core pillars of activity is to advance meaningful NET research through active patient involvement in defining the global research agenda.
- Recognizing the significant value of informed patient input, INCA developed a training program to educate the community about its place in research.

### METHODS

- The INCA Research Committee contracted an agency with extensive knowledge in delivering trainings to patients on research expertise.
- The agency developed and led a 9-month online training program which was free for all participants – NET patient advocates representing member organizations of INCA. The course utilized Google Classroom to allow the sharing and dissemination of reading materials, homework assignments and the recordings of the online sessions.
- Each session was accompanied by a homework assignment.

### RESULTS

The Boot Camp for Research Patient Advocates took place from June 2020 until February 2021.

The course itself was an intensive training program aimed **to educate leading NET patient advocates who would further share their newly-acquired knowledge in their local communities.**

All INCA members were invited to:

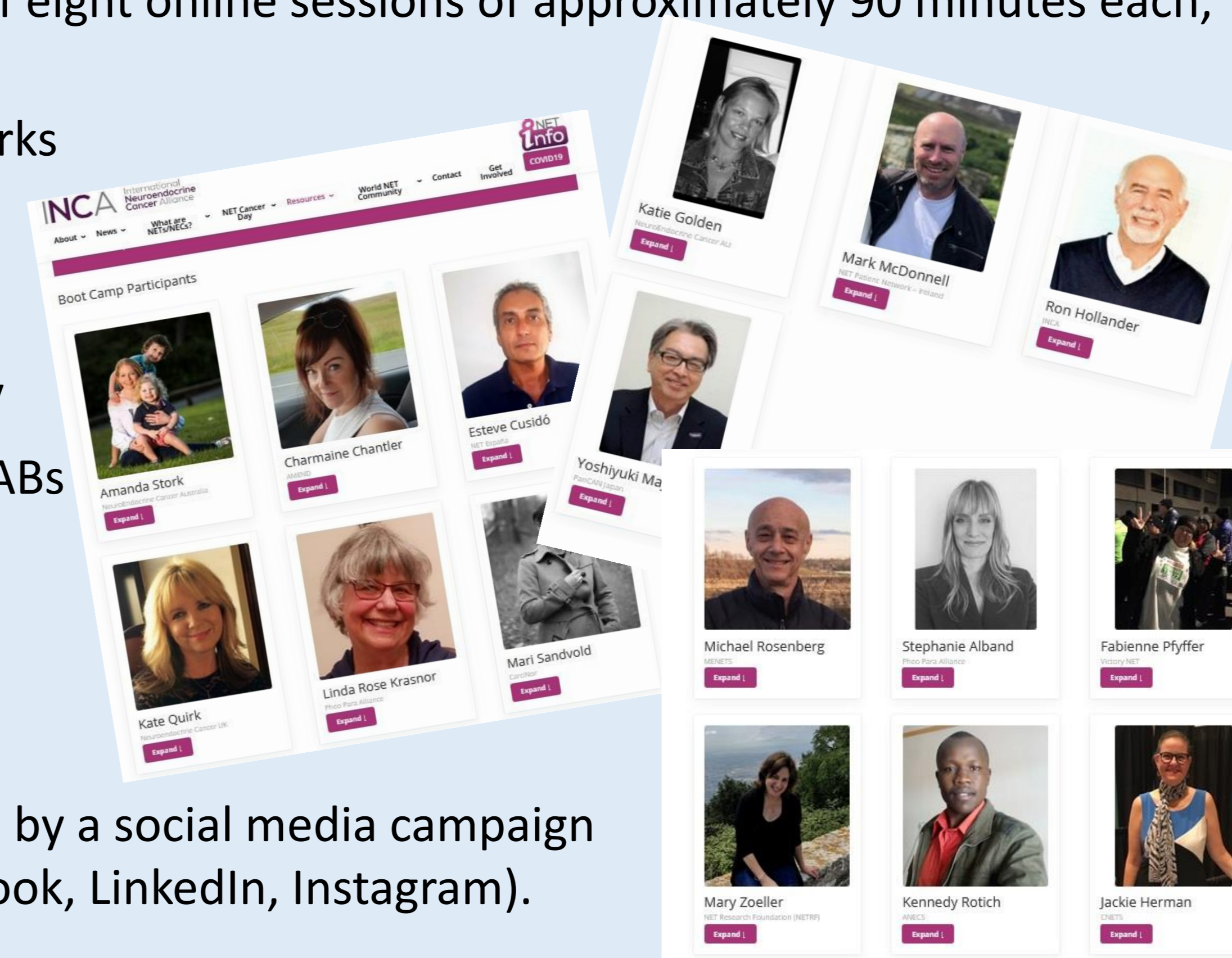
- Nominate active and engaged representatives from their respective organizations;
- Encourage the nominated candidates to further disseminate what they have learned during the course.

The training opportunity was met with enthusiasm:

- **18** participants from **14** different countries across **5** continents registered for the course.

The INCA Boot Camp was comprised of eight online sessions of approximately 90 minutes each, and discussed the following topics:

- How medicines development works
- Statistics and why they matter
- Importance of PROs and QoL
- Evidence-based patient advocacy
- Patient advocacy in action and CABs
- From R&D to access



The INCA Boot Camp was promoted by a social media campaign (#INCABootCamp on Twitter, Facebook, LinkedIn, Instagram).

All participants were profiled in the INCA newsletter and on the INCA website where a sub-page was developed to boost awareness and information about the project's goals and output. <https://incalliance.org/bootcamp/>

### CONCLUSIONS

- The INCA Boot Camp for Patient Research Advocates enabled a unique pool of global NET patient leaders to acquire valuable, in-depth knowledge of the drug development process and evidence-based advocacy and further propel it within their respective communities.
- The targets set by the INCA Research Committee were reached, as all participants reported a greater understanding of the clinical trials processes and terminology, as well as various measurements for patient outcomes and improved knowledge of tools for more efficient patient advocacy in research at the end of the course.
- Equipped with valuable knowledge and skills, many of the graduates foresaw a proactive approach in joining clinical trial boards and sub-committees to voice the patient perspective both during the course as well as after its conclusion.
- A strong sense of community was fostered with the prospect of continually getting the graduates involved as a group so that they can learn from each other and reinforce their education, which is vital to nurturing their newly acquired skills.
- INCA will manage and oversee that process and have them involved individually as representatives of their respective organizations, as well as INCA. A series of podcasts and webinars with the graduates presenting on various topics from the course is envisaged.

### ACKNOWLEDGEMENTS

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Learn more at @NETCancerDay [www.incalliance.org](http://www.incalliance.org) #INCABootCamp #LetsTalkAboutNETs