PCDC Public Webinar - May 18, 2022
Q&A Text Transcript

Questions that were answered via the text Q&A and chat functions in Zoom are reproduced below. If you have any additional questions that are not addressed below, please reach out to us!

Q: How do you see working with Patient Advocacy Organizations and using their close connection to families to facilitate opportunities for patient families to engage with and collect patient experience data?
A: *(from Kathy Pritchard-Jones)* Kim, thank you for the question, in Europe, we work closely with CCI-Europe (Childhood Cancer International) and have set up a working group that focuses on parent/patient involvement in research.

Q: Given the costs associated with running trials, how should we weigh the cost-benefit of opening trials in LMIC versus maybe using those same resources for promoting essential diagnostic and data collection in those same countries?
A: *(from Kathy Pritchard-Jones)* It will depend on how a clinical trial is defined in each country – from SIOP's perspective, we advocate for more clinical research in LMICs in order to generate locally relevant evidence applicable to the region's population. Introducing a new standard of care may be seen as a 'trial' in that setting. Equally important, may be to ask a particular therapeutic question for a defined population where therapy is 'adapted' to local resources and/or genetic background of specific populations (e.g mis match repair defects in children with brain tumours in Jordan). Both need resources to establish the culture and infrastructure to collect high quality prospective clinical data.

Q: Suzi, The process outline you mentioned: is it available on the website? If not can we put in some details of the process?
A: *(from Suzi Birz)* Thank you. Yes, we are working on a document for the website now. The publication policies for each disease - which address this at a high level and the project application / request forms are available on disease webpages on https://commons.cri.uchicago.edu/