Euro-Ewing’s Consortium:
the voice of parents and patients in a major European research trial

Chris Copland
Consumer Representative
Children’s Cancer and Leukaemia Clinical Studies Group.
National Cancer Research Institute
Aims

• to explain what Euro Ewing’s is

• to show why the work of the EEC is a concern of the CCI

• to show how members can help
What is Ewing’s Sarcoma?

A bone cancer that affects children, adolescents and adults.

Cases peak in the teenage years.
Factors in common with other teenage cancers

• Rarity
“Slightly fewer than two cases of Ewing's sarcoma diagnosed per million people in the general population in Europe each year…”

• Poor survival rates
“The overall… rate is now around 60 %... It has only slightly improved over the last 20 years..” (BCRT 2010)
A pan-European project

With rare illnesses, it is necessary to recruit beyond national boundaries.

• 2 trials to open in 17 countries across Europe
• target of at least 1000 participants in first 5 years
What does EEC do?

It runs two trials:

Euro-Ewing’s 2012 (at primary stage)
   to optimise the balance of the chemotherapy drugs
   that have been, more or less, the standard treatment
   since the 1970’s.

rEECur (on relapse)
   to compare chemo drugs frequently used at relapse
   and establish a *backbone* against which to compare new
treatments
What does EEC not do?

Ambitious in scale / modest in aims

• does not include new agents 
  (with exception of zoledronic acid)

• does not attempt to lift Ewing’s off the’ plateau’
How can EEC evolve?

Now trials are running, possible to add new agents, e.g., ESPRIT, which tests a PARP inhibitor that targets DNA repair mechanism.

*However*, before rEECur can introduce a new agent, has to drop one of the four arms being tested - unlikely to happen for two years.
Patient public input

EEC aims to develop European network of PPI via Sarcoma Patients Euronet (SPAEN)

• influence how EEC should evolve
• lobby on issues such as making tissue samples available for research
• review patient information sheets
• provide support to families,

Can CCI help recruit?
Postscript: lost opportunities

IGF1R inhibitor – significant potential shown for subset of Ewing’s patients. Pediatric Investigation Plan stalled when trials into adult lung cancer unsuccessful. (Baruchel et al. 2012)

PARP inhibitor – AstraZeneca trials on ovarian cancer granted class waiver for Pediatric Investigation Plan. (Capel. 2013)

Urgent need for patient advocacy
Over to you

chriscoplanyork@gmail.com
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