



Why a CAB?

What we learned so far!

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Lymphoma Coalition - Regional Manager,
Europe

Eurordis Membership Meeting 2019
Bucharest 17 & 18 May 2019 - Bucharest,
Romania



Global Network of Patient Groups

Facilitation and Resource Centre

to create a level playing field of information



- Since 2002 – incorporated in 2010
- 81 member organisations - 51 countries
- Global Board of Directors
- Global Medical Advisory Board
(access to +70 around the world)
- Patient leaders in all blood cancers
- Gather and disseminate information on all lymphomas including CLL
- Think Global – Act Local
- 650,000++ database

Laurie Sehn, <i>Chair</i>	Canada
Andreas Engert	Germany
John Gribben	UK
Gilles Salles	France
John Seymour	Australia
Julie Vose	USA

WHY...?

**WHAT
FOR...?**

perception

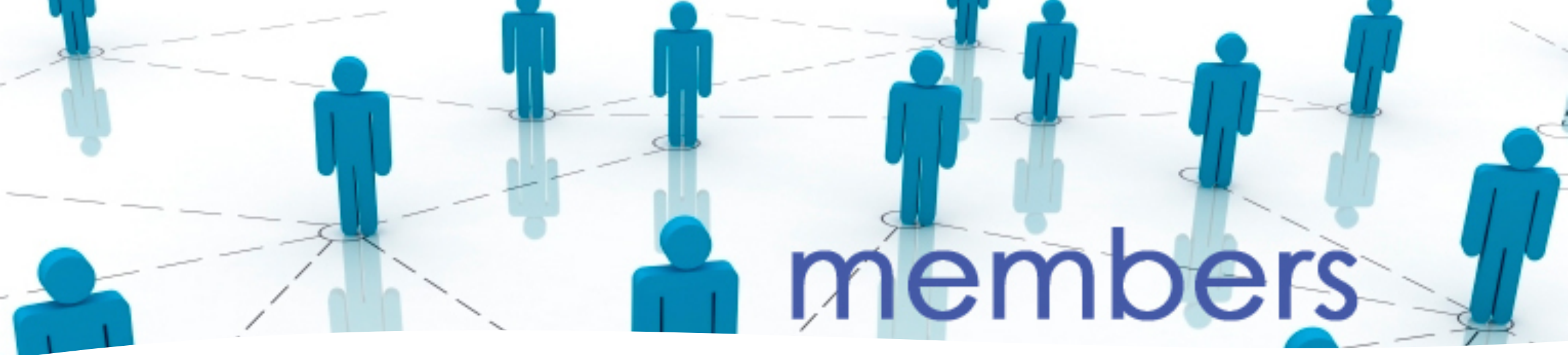
**Changes the dynamic
of the relationship
between industry and
patient organisations**



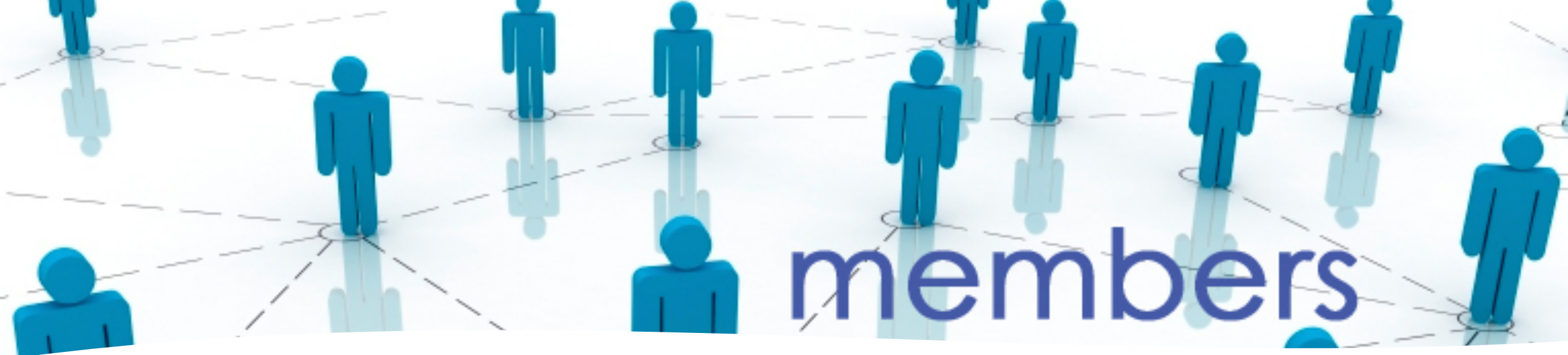


The CAB appreciates the opportunity to have a closer look at the full clinical trial protocols, ICFs, etc, in the future:

- It was advised to involve the patient community (CAB) **early in the trial design** process and **ask their advice to make documents such as the ICF (and any other patient education documents)** transparent and understandable.
- Being more **actively involved in the pipeline** studies
- Involvement in the **site selection for clinical trials**



- ✓ “Especially as we were first time gathering live so this was a must. Also preparation for the meeting was also good that we know what to ask and what's our aim and scope.”
- ✓ “These questions are difficult for me to answer as I have not previously attended meetings with pharma companies, so I had no expectations. I found the staff friendly and approachable. it seems that they are keen to embrace the idea of a CAB and are willing to participate in a good way, although they seemed very keen not to overshare information.”



- ✓“Fully trained before they arrived and this was obvious. they had an extremely approachable, genial manner and were keen to involve each of us in discussions. This was the only meeting where I felt they appreciated that I had a lack of scientific knowledge but were eager to hear from a patient perspective.”
- ✓“It felt as though we were being lectured and if discussions did not go to plan or questions were difficult!”



Pharma Industry

What were the three most valuable things pharma representatives learned at the CAB?

- ✓ Need to integrate patient voice in PROs/CT
- ✓ Collaboration is key, there is much to learn from each other!
- ✓ Feeling on what impact "small" changes from our perspective might have on pts / caregivers life

what do
YOU
expect?

CABs commonly formalize the industry–patients partnerships that guide research, by providing a mechanism for community members to have representation in research activities

CAB is a paradigm to study and reduce disparities in health outcomes