

Community Advisory Boards in Rare Diseases



Can patients change the clinical study paradigm?

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Introduction: Patient Community Advisory Boards (CABs) are groups established and operated by patient advocates. They facilitate discussions in a neutral setting on the latest developments and challenges related to medical research and procedures in their disease area with the company or sponsor conducting the research. By being involved before a clinical study starts, patients help ensure that clinical studies are designed to take into account their real needs, resulting in higher quality research. CABs can also be involved in policy-related issues like access. They provide expert advice to all stakeholders involved in the research, development and service provision of medical treatments.

The EUROCABs programme will offer:

Unique Guidelines and Specific advice

The CHARTER

The Memorandum of Understanding

The Code of Practice

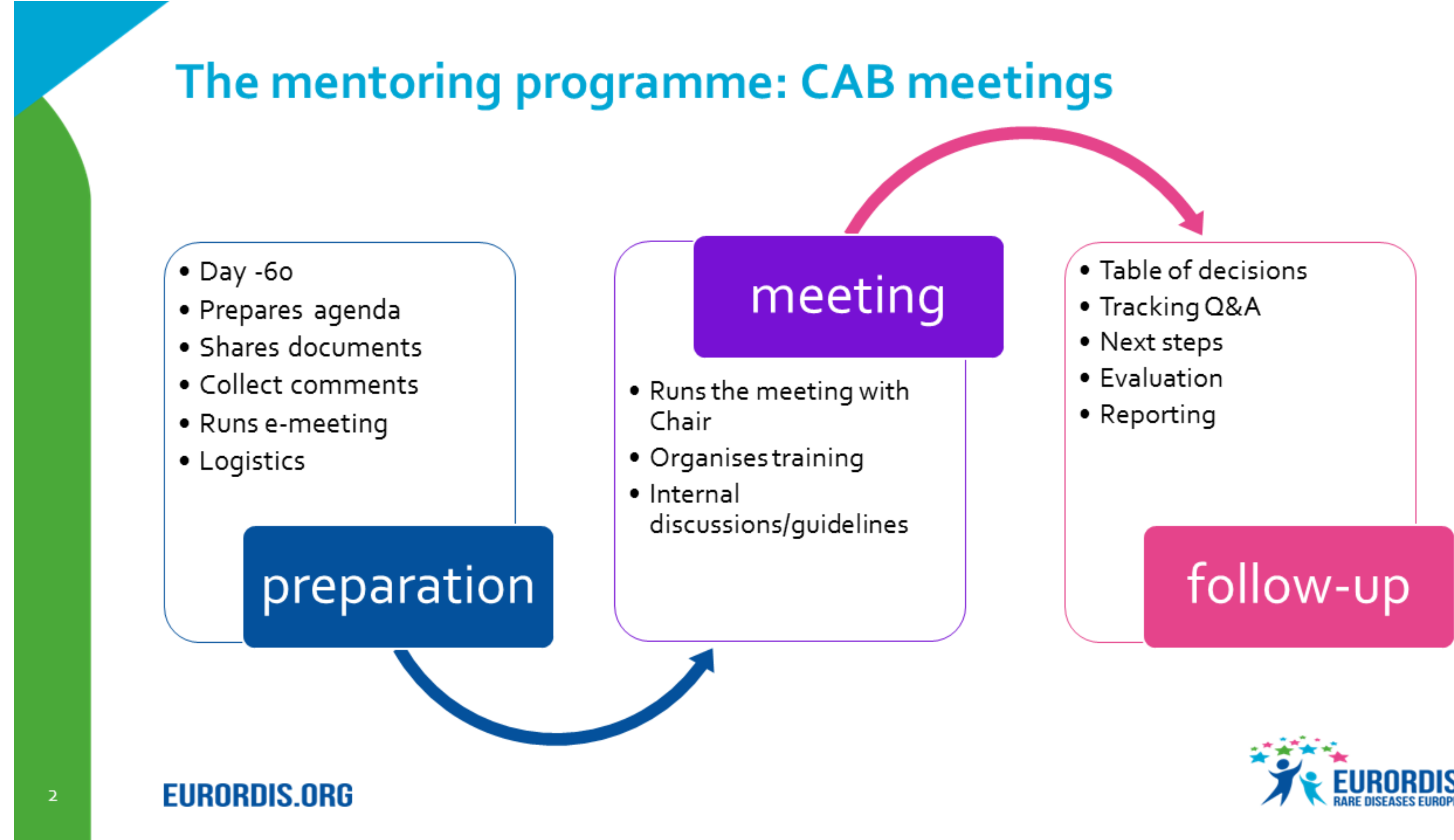
A Mentoring Programme

The EUROCAB website

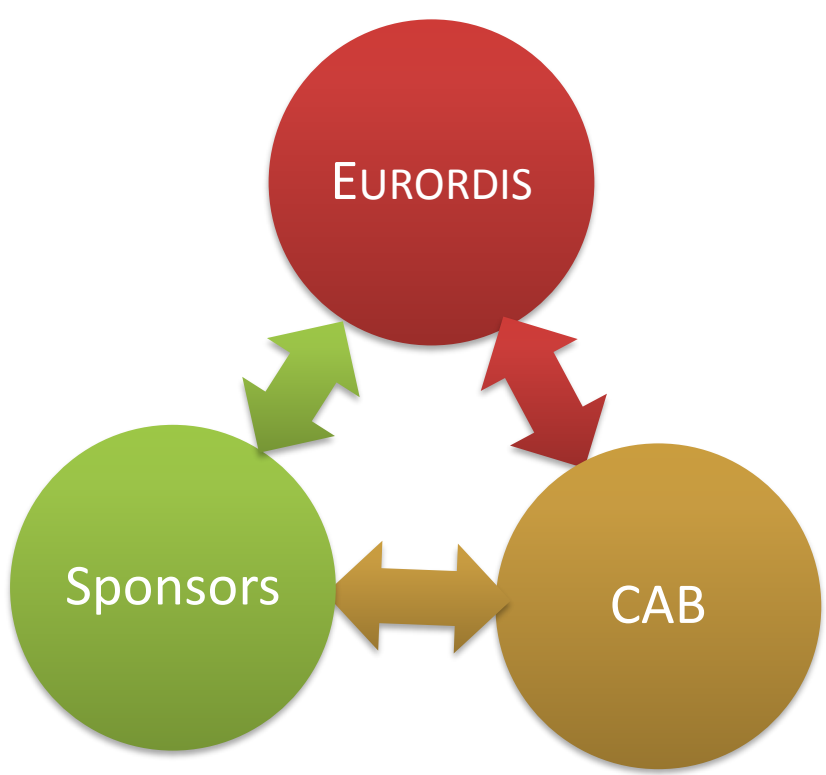
Training and preparation (ie, clinical trials; negotiation skills)

Administration (budget, logistics)

The EUROCAB seal (quality assurance)



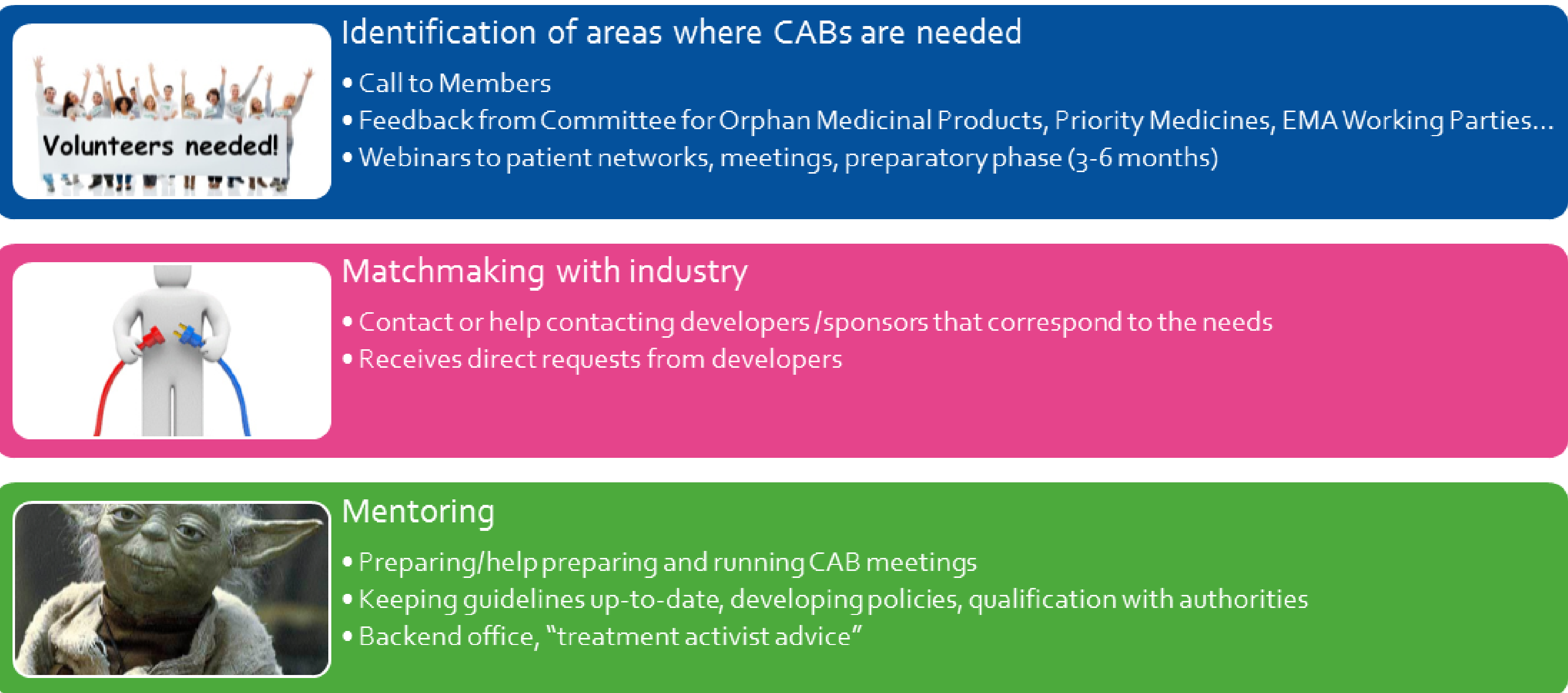
Results: Throughout history, medical science has evolved with little to no input from the people being studied. Actually, the disease is being studied, where the patient is nothing more than the vessel! CABs change that, and help to design, carry out and communicate on studies that are more rational and inclusive from a patient's point of view. By doing so, a bond of trust between the patient and scientific community is formed. Since the '90s, CABs have operated in a number of disease areas and have contributed to the amelioration of HIV and the cure for hepatitis C, for example. We are looking forward to similarly successful results in rare diseases.



Discussion: The EUROCAB programme will give you: **Experience:** CABs benefit from experienced advice on how to operate a CAB and to do it right; **Training:** CABs benefit from EURORDIS training programmes (Summer School, Winter School); **Credibility:** CABs benefit from EURORDIS credibility and strong governance; **Standard:** CABs may qualify for regulatory procedures as “patient investigators”; **Up-to-date:** CABs will be aware of all new initiatives along the products life-cycle; and **Visibility:** CABs become more widely known!

EUROCAB website coming soon.

The EUROCAB programme: incubator, mentor, advisor



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