

Growing a heart patient advocacy group

How can cardiovascular patient organisations professionalise?

New advocacy organisations are like new businesses: they begin the start-up phase fuelled by enthusiasm and a belief that their work is of value. What they lack in funding and manpower, they make up for in energy and drive. However, as they develop and grow, campaigners face the same risks as fledgling companies – they may struggle to raise funds and to establish a strong public identity.

Some founders burn out when the initial burst of enthusiasm fades, finding that they lack the people and skills required to take their operation to the next level. Others discover ways to expand their operations, attract people to their cause and put their organisation on a sustainable path. The question is: what separates the survivors from the rest? The experience of successful advocacy groups suggests that setting and keeping core values is vital, while formally establishing charities or foundations may bring recognition and open new funding opportunities.

Top tips for going pro

1. Stay true to your mission, but review your strategy as you grow
2. Identify collaborators, build your network and tap into existing resources
3. Ask not only what volunteers can do for you, but what you can do for volunteers
4. As the organisation expands, think carefully about your capacity to manage volunteers
5. Consider the legal status, governance and accounting practices required to attract staff and funding

Many health advocacy groups are founded by patients, families or clinicians who see an unmet need to raise awareness, improve services or support research. For example, a loose network of parents or carers providing peer support might set up social media groups or begin fundraising. A key question is when, if at all, to become a legal entity. For Marc Bains, Co-Founder and Vice President at the HeartLife Foundation, Canada, making that leap was essential to sustainability.

‘Our three founders saw a need to have people supporting those living with heart failure and to be available to speak with personal experience about the disease,’ he says. ‘The first step was to define our mission and values, and then find ways to increase our impact without expanding the size of our team and our office.’ The Foundation has mobilised a network of

volunteers and champions, while nurturing relationships with external local and global partners. ‘My advice is to look to amplify your voice by working with those who have skills and resources that you may not have,’ says. ‘The old saying rings true: *if you want to fast, go alone; if you want to go far, go together.*’

Surviving and thriving in uncertain times

Start-up advocacy groups must navigate the complexity of health, political and fundraising systems if they are to endure turbulent times. For FH Europe, a growing organisation highlighting the preventable risks associated with inherited hypercholesterolaemia, adapting to COVID-19 and the uncertainties caused by the war in Ukraine have brought unexpected challenges. However, small organisations have the advantage of being nimble: they can adapt to survive.

Magdalena Daccord, Chief Executive, FH Europe, says the pan-European organisation’s early years were characterised by the tireless work of volunteers, many of whom also worked in other organisations. ‘As we grew, they were overloaded and we needed to restructure to become a fit-for-purpose legal foundation,’ she says. ‘We are also relocating to another country to tap into new funding streams while respecting our ultimate mission. My message is that failures and mistakes are part of the growing journey. It’s about what we learn along the way.’

Jon Barrick, Stroke Alliance for Europe (SAFE) Ambassador and ex-CEO, UK Stroke Association, highlighted the tension between harnessing patient power and being overly reliant on a small group of volunteers. He argues that advocacy groups should focus on what they offer to volunteers – such as experience and a sense of purpose – and seek out specific skill sets. ‘Think of their age and their needs. Some want to build their CVs, some are seeking social interaction, others are looking for proximity to power,’ he explains. ‘But think seriously about who is going to manage your network of volunteers. Try to attract retired managers who may be willing to share their expertise.’

Appointing a strong board can also help to establish good governance practices and ensure the organisation’s mission is reflected in its strategy. People with legal and accountancy experience, fundraising connections or political influence can be particularly valuable. ‘Ultimately, you need to put yourself in a situation where you cannot be ignored,’ Mr Barrick says. ‘Be credible, build connections, engage with the media and prominent medics, and ensure you have a seat at the table.’

Case study: transforming a parents’ network into a hospital foundation

The remarkable story of *Comitato Maria Letizia Verga* began 42 years ago in the Lombardy region of Italy. It began as an informal network of concerned parents whose children were being treated for leukaemia. Their motivation stemmed from a shared sense that paediatric oncology care was inadequate. In the absence of a children’s cancer centre, young patients were treated in an adult general hospital in Milan. As their number grew, the group formed an association and began to raise funds and campaign for a more holistic approach to paediatric care.

Fast forward a couple of decades and the association had evolved from a peer-to-peer support group to an influential organisation established as two foundations – one dedicated to medical research, the other to enhancing care. In a remarkable turn of events, the care-focused foundation took over a paediatric unit in a hospital in the city of Monza. Following the donation of an empty building, the unit was then established as a stand-alone paediatric hospital. It is now a globally recognised national reference centre for children’s cancer.

Dr Elisabetta Notarnicola, SDA Bocconi School of Management, Italy, says the foundations' success followed a long collaboration with local public health authorities, hospitals and universities. 'Over time, the organisation became more professional and more formal with a defined governance team,' she says. 'This allowed it to sign contracts and to shift from direct advocacy to the provision of services. It has balanced the need to evolve its mission while retaining its values.'

Inspired by discussions at the Global Heart Hub UNITE Summit 2022