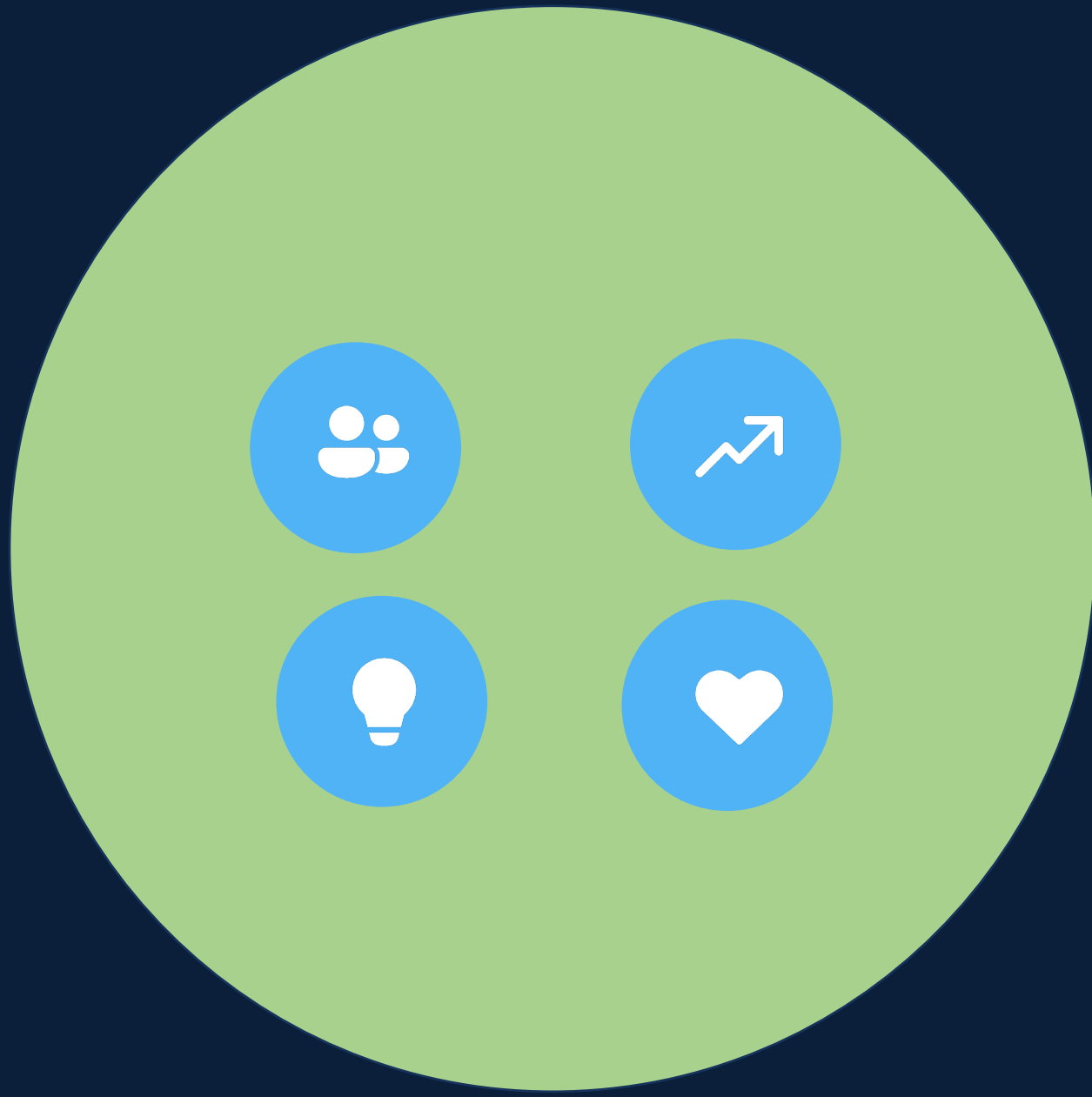
VHL UK / Ireland

Strategic Intent 2026- 2030

Vision · Mission · Strategic Pillars



Vision

Become the “Golden Source” for all VHL matters in our chosen territories (UK & Ireland)

For Patients, it means becoming the first port of call for authentic and reliable education and information relating to VHL

For Clinicians and Researchers, it means becoming a “Trusted Partner” and being recognised as the truly representative Voice of VHL Patients

For other stakeholders, it means becoming a credible “expert witness” for VHL Patients

Mission

We will, as part of our DNA:



Have ALL Patients at the heart of every decision



Raise the bar in terms of what is possible



Build expertise and Empower people to Focus and Deliver on the Core goals



Remind ourselves regularly why we give of our time, energy and emotions FREELY

Patient

Have ALL Patients at the heart of every decision

Belzutifan

HSE Ireland Belzutifan Appraisal

Do everything possible to support patients in Ireland to achieve a positive outcome

NHS England, Wales and NI - CDF Belzutifan Appraisal deadline Sep 2029

Enrol support of Health Economist specialism if required, and be prepared to raise funding toward the cost

Medical Advisory Board (MAB)

Implement “MAB” to (inter alia) support patient clinical questions / provide expert impartial input to assess research grant requests

Patient Engagement

Patient Days to be Annually, and rotated geographically (5-yearly rotation) around UK and Ireland

Patient Events (Teams) on specific topics to become part of what we do- starting early 2027 with Belzutifan access

Voice of the Patient

Patient Ambassadors to become a vital link between “local” clinics and clinicians, and extend reach of the Charity

GROW

Raise the bar in terms of what is possible

Collaboration- VHL Alliance and VHL Europa (plus other European VHL Charity bodies) related

Ensure “Regular” sharing of plans/ goals

Collaboration- Other Specific Cancer Charities

Work with other cancer charities on common goals of mutual interest and patient benefit

Fundraising and Donations

Avoid risk of fundraiser fatigue amongst current limited fundraising pool / Create frictionless support for fundraisers

Identify key potential donors- win their hearts and minds with a compelling STORY which articulates the VHL niche

SIMPLIFY

Build expertise and Empower people to Focus and Deliver on the Core goals

Charity Identity

Remove or reduce messaging ambiguity (internal and external) re Core Population served

Make explicit the roles of “VHLA” & “VHL “Europa” as distinct from VHL UK & Ireland

Internal

Clarify functions and their remit / have clear heads for each function and clear teams for each function

Implement a transparent decision-making framework

Delegate powers to teams to act on issues according to level of materiality & budget and “in-Team” expertise

Network

Build a network of occupational experts to support the Charity

Culture

Remind ourselves regularly why we give of our time, energy and emotions freely, and celebrate rather than apologise for that fact

Seek out experts

Foster a culture of learning from experts and others outside the team

Celebrate an “I don’t know, so let’s ask outside for help and expertise” response to issues

Empowerment

Empower where we have true “occupational expertise”

Trust colleagues when operating within delegated powers