European Reference Network

ERN eUROGEN
Rare Uro-Recto-Genital Diseases
& Complex Conditions

# Patient Empowerment:

## A Journey From Isolation to Advocacy

## Recognising “Common Needs in Uncommon Conditions”

Isolation → Empowerment → Advocacy

*This flyer has been adapted from work by patient representatives from* ***VACTERL Association UK, TOFS,*** *and* ***Max’s Trust****, representing a broad spectrum of* ***v****ertebral,* ***a****norectal,* ***c****ardiac,* ***t****racheal,* ***e****sophageal,* ***r****enal, and* ***l****imb conditions. Their lived experiences have shaped this journey, highlighting the* ***common*** *challenges faced and pathways used by adults across* ***different*** *rare conditions, and thereby emphasising the importance of* ***empowerment*** *and* ***advocacy****.*

tofs lifelong support for those born unable to swallow

VACTERL Association Support Group

Max’s Trust
Providing support and information to the UK Anorectal Malformation Community

## Living with a Rare Condition in Isolation

- **Personal struggles. Yearning for wholeness** – Did our best. Got by. Doable but life was hard. Always knew pieces were missing. Always treading water when instead needed to swim to go forward.
- **Lives Journeyed Alone** – Felt overwhelmed, lonely, isolated, vulnerable, trapped, exhausted, in pain. Questioned identity, self-worth, purpose and place in the world. Not living in the moment - focused on managing daily care needs.
- **Feeling separate from others** – Unshared joy; when things went well (e.g., with personal care) unable to share our experiences - others may be repulsed as they do not understand our care needs.
- **Struggling for Answers** – Uncertainty, unable to rely on healthcare professionals for advice: “You are too complicated.”
- **Psychological Burden** – Tried to make sense of what we didn’t understand - “Am I the problem?”. Ineffective coping strategies. Fear, defensive behaviours, anger, grief, confusion, frustration, hopelessness. Survival mode - anxieties about the future, for self and genetic inheritance.
- **Invisible Challenges** – Hidden disabilities are misunderstood; our external appearance doesn’t reflect our internal struggles. Stigma, discrimination, exclusion, marginalisation.
- **Barriers to Life** – Inaccessibility and lack of representation. Work, relationships, and daily life affected. Felt unable to progress in life.

## A Shift Towards Empowerment

- **A Turning Point** – Challenging or disappointing healthcare experiences - a single event or many episodes may spark change. A light bulb moment, a wake-up call to find the tools to take control, to navigate our own healthcare journey.
- **Gain Knowledge** – Learning about one’s own medical history, condition, medical terms, treatment options (medications/operations), and “red flag” symptoms. Able to have open relationships with care team - patient and professional both learning from each other. Unanswered questions are finally resolved. Finally being heard.
- **Becoming an Active Participant** – Starting to trust healthcare professionals, listening to them and becoming receptive to their advice. Journeying from being a passive recipient to being engaged, taking control of healthcare decisions, advocating for holistic care. The value of lived experience: “You are the expert on your condition.”
- **Acceptance** – Acknowledging feelings and experiences, going through grieving process, embracing differences, building resilience, coming to terms with the future.
- **Lives Journeyed Together** – Building connections with others walking the same path. Support networks, peer-to-peer groups, patient organisations provide belonging, community and hope.
- **Validation & Representation** – Shared experiences, acknowledgement, and focus on strengths, not just medical conditions (seen as a whole person). Empathy, communication, encouragement and support from family & friends.

## Becoming an Advocate

- **Self-Advocacy** – Finding our own voice, self-determination, and confidence to communicate in our preferred way. Learning to adapt to different professionals/different situations.
- **Advocating For & Empowering Others** – Sharing personal stories to help others. Signposting, mentoring, and helping others communicate their needs in ways they are comfortable with (e.g., using a medical passport). Providing hope for those newly diagnosed and their families.
- **Parent-Child Relationships (when applicable to condition)** – Able to understand parents' perspectives; they too have walked a difficult path; they too have experienced the isolation which surrounds rare and complex conditions, being outside the social norm. Valuing their journey and the difficult decisions they had to make about care. Listening to their stories. Understanding they may have unresolved grief.
- **Community & Collaboration** – Supporting and looking out for each other. Sharing knowledge, resources and ideas. "Everyone is heard; everyone is valued."
- **Partners in Care** – Working alongside healthcare professionals to challenge & overcome barriers and improve systems.
- **A Beacon of Hope** – Embracing identity beyond the condition, promoting inclusion, fostering empathy and compassion.

## ERN eUROGEN: Rare Uro-Recto-Genital Malformations

ERN eUROGEN connects healthcare providers and patients across the EU/EEA and Ukraine, and providing equitable access to diagnosis, treatment and care across three workstreams:

- Workstream 1: Rare congenital uro-recto-genital anomalies (children)
- Workstream 2: Functional uro-recto-genital conditions requiring highly specialised surgery (adults)
- Workstream 3: Rare uro-recto-genital tumours

**Learn more...**

🌐 **eurogen-ern.eu**

### The ERN eUROGEN European Patient Advocacy Group (ePAG)

Plays a key role in all activities, especially in governance, dissemination, evaluation, education, and developing clinical guidelines and patient information. Several patient organisations support and contribute to ERN eUROGEN's mission:

- AICI (Italy)
- Orchid (UK)
- AIMAR (Italy)
- SoMA eV (Germany)
- KSA (UK)
- EAT (UK)

Finding patient organisations and representatives in this medical area can be difficult, so new applications from patients to work with ERN eUROGEN are warmly welcomed.

AICI
ASSOCIAZIONE ITALIANA
CISTITE INTERSTIZIALE

AIMAR

eXtra
Klinefelter's
Syndrome
Association

ORCHID
FIGHTING MALE CANCER

SOMA

EAT
Esophageal ATresia
Global Support Groups

Funded by
the European Union

**Share. Care. Cure.**