TOOLS FOR THYROID

A Guide to Starting and Sustaining a Thyroid Patient Organization

Published by Thyroid Federation International (TFI)



thyroid-federation.org

Thyroid Federation International

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Part 1: Understanding the Landscape

1. What Is an NGO?

An NGO (Non-Governmental Organization) is a voluntary, non-profit organization with a social mission that operates independently from government institutions.

NGOs conduct activities to ease suffering, support disadvantaged groups, provide essential community services, and promote community development. They play a crucial role in society through their humanitarian, social, political, and economic activities.

2. What Is a Patient Organization?

According to the European Medicines Agency (EMA), a patient organization is defined as:

> *"A not-for-profit organization that is patient-focused, in which patients and/or carers (when patients are unable to represent themselves) constitute a majority of the members in the governing bodies."*

Patient organizations aim to:

- **Empower patients** to take an active role in managing their health
- **Represent patient rights** in healthcare policy discussions
- **Bridge the gap** between individual patient needs and broader healthcare system decisions
- **Provide reliable information** that helps patients make informed decisions

3. The Importance of Thyroid Patient Empowerment

Empowerment is a multidimensional process that enables people to gain control over their own lives and strengthen their ability to act on issues they define as important.

Thyroid diseases are chronic conditions affecting more than 200 million people worldwide. These include hypothyroidism, hyperthyroidism, Hashimoto's disease, Graves' Disease, Thyroid Eye Disease, thyroid cancer, goitre, thyroid nodules, and several rare conditions such as MCT8 deficiency. Many patients go undiagnosed for years, and even those diagnosed often struggle with ongoing symptoms, treatment adherence, and quality-of-life challenges.

Patient organizations play a fundamental role in:

- **Raising awareness** about thyroid diseases and closing the knowledge gap
- **Supporting disease management** through education and peer support
- **Influencing healthcare policies** to ensure adequate treatment access
- **Advocating for patient rights** including access to a range of treatment options

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- **Reducing stigma** associated with chronic thyroid conditions
- **Promoting early diagnosis** through screening awareness campaigns

4. The Global Thyroid Patient Organization Landscape

Thyroid Federation International (TFI)

TFI is a global, non-profit network of patient organizations with more than 40 member organizations from all continents — both patient-led and patient-oriented — that aim to support thyroid patients worldwide. Founded in 1995 at the 11th International Thyroid Congress in Toronto, TFI grew from the vision of Diana Meltzer Abramsky, who in 1980 founded the first patient-oriented thyroid organization in the world.

TFI's core objectives:

- Assist the creation of thyroid patient organizations worldwide
- Work closely with medical professionals to promote understanding of thyroid disorders
- Inform and support thyroid patients with evidence-based information
- Participate in international congresses and policy forums

TFI actively participates at the European Thyroid Association (ETA), American Thyroid Association (ATA), European Congress of Endocrinology (ECE), European Society of Paediatric Endocrinology (ESPE), Asian and Oceania Thyroid Association (AOTA), and Latin American Thyroid Society (LATS), and is a member of EURORDIS and European Cancer Organisation (ECO).

Learning from Established Organizations

What established organizations offer:

- **Patient education libraries**: Established national organizations have patient education brochures covering adult and paediatric conditions, patient portals, and multilingual resources spanning the full range of thyroid conditions.
- **Membership and newsletter models**: Established national organizations typically operate membership programmes with thousands of members, publish regular newsletters and free health guides, host webinars with thyroid specialists, and conduct public education events with medical experts.
- **Condition-specific organizations**: Some TFI member organizations focus on a specific thyroid condition such as Graves' Disease, Thyroid Eye Disease, or thyroid cancer, providing specialist peer support and targeted advocacy.

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- **Multilingual resources**: Some member organizations provide patient handbooks and materials in multiple languages, making information accessible to diverse communities around the world.
- **Online patient communities**: Patient-run organizations with research-based content, active online communities, and discussion groups help patients stay informed and connected.
- **Helplines and support services**: Well-established patient organizations typically offer patient forums, online support groups, medical query services assisting thousands of patients annually, and volunteer helplines. Their patient materials are medically endorsed and available in multiple languages.
- **Patient advocacy organizations**: Advocacy-focused organizations work to promote effective diagnosis and appropriate treatment, hosting large online communities and advocating for expanded treatment access and patient rights.
- **Community education programmes**: Many member organizations run national or regional educational programmes, providing support and information to members and families across all life stages, including iodine deficiency awareness.

International Medical/Professional Societies (collaboration partners):

- European Thyroid Association (ETA) — eurothyroid.com
- American Thyroid Association (ATA) — thyroid.org
- Latin American Thyroid Society (LATS) — lats.org
- Asia and Oceania Thyroid Association (AOTA) — aota.kr

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Part 2: Starting Your Patient Organization

5. Your Story: Why Start a Patient Organization?

Patient organizations often originate from the sharing of personal experiences. A personal diagnosis — whether hypothyroidism, Graves' Disease, Hashimoto's thyroiditis, or thyroid cancer — often becomes the catalyst for helping others facing the same challenges.

Example — A Personal Story

A diagnosis of Hashimoto's thyroiditis initially led to denial and underestimation of the disease. Over time, persistent symptoms and the later diagnosis of the same autoimmune condition in the child highlighted the lifelong impact of thyroid disease. This experience became the driving force behind founding a patient association aimed at providing support, expert medical information, and empowerment for patients and families.

Reflecting on Your Motivation

Before starting, consider:

- What gaps related to thyroid patient support exist in your country or community?
- Is there already a thyroid patient organization you could join or collaborate with?
- What unique perspectives or resources can you bring along?
- Are there healthcare professionals willing to support and advise?
- Can you connect with TFI for advice, affiliation?

6. Defining Purpose, Vision, and Goals

The first essential step in starting an organization is defining its purpose.

Vision Statement

A vision statement describes the long-term goal an organization aspires to achieve. A strong vision:

- Inspires patients and society
- Is clear and easily understood
- Describes a future-oriented goal
- Reflects progressive and inclusive values

Example Vision Statements:

- "[Name of organization] is a non-governmental and non-profit association founded to support patients with thyroid diseases and empower them to live well."

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- "A world where every person with a thyroid condition has access to early diagnosis, effective treatment, and ongoing support."
- "Improving the lives of people affected by thyroid disease through awareness, education, and advocacy."

Possible Organizational Goals

- Raising awareness of thyroid disease frequency, causes, and treatments
- Promoting multidisciplinary approaches to prevention and care
- Creating patient and physician databases / directories
- Supporting children with thyroid disease and their families
- Providing reliable, evidence-based medical information
- Promoting healthy lifestyles and nutritional awareness (including the importance of iodine for thyroid health)
- Supporting early diagnosis and modern treatment of thyroid cancer
- Promoting screening and preventive laboratory testing
- Reducing diagnostic delays through public education campaigns
- Addressing mental health and quality-of-life challenges faced by thyroid patients
- Advocating for expanded treatment options and access to all available therapies
- Providing multilingual resources for diverse communities

7. Mission Statement

The mission statement explains how the organization will achieve its vision. A good mission is:

- Clear and concise
- Realistic and achievable
- Focused on measurable outcomes

Example Mission Statements:

- "To promote early diagnosis of thyroid diseases through public awareness campaigns and screening advocacy"
- "To raise awareness of autoimmune thyroid disorders and support patients with evidence-based information"
- "To support patients in daily life challenges through peer support, education, and advocacy"
- "To encourage healthy lifestyles to prevent complications, including iodine nutrition education"

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- "To advocate for a multidisciplinary approach to thyroid care and expanded treatment access"
- "To educate patients, doctors, policymakers and the public about thyroid health"



Part 3: Establishing Your Organization

8. Legal Establishment of the Association

General Principles

Legal requirements vary significantly by country. The following general guidance should be adapted to your local legal framework. Always consult a local attorney or notary familiar with nonprofit law in your jurisdiction.

Common Requirements Across Jurisdictions

Founders:

- Most jurisdictions require a minimum number of founding members (often 3 or more)
- At least one founder typically must reside in the country of registration
- Founders may be individuals or legal entities (domestic or foreign)
- Public authorities generally cannot be founders

Registration Procedure (varies by country, but typically includes):

- An application to the relevant government registry (e.g., Register of Associations, Charities Commission, Corporate Affairs)
- Registration for tax identification and any applicable tax-exempt status
- In some countries, charitable or nonprofit status provides tax benefits for donations

Common Required Legal Documents:

- Founding Act / Articles of Incorporation / Constitution
- Statute / Bylaws of the Association
- Minutes of the founding meeting
- List of founding members and governing body

Tax-Exempt / Charitable Status:

- Many countries offer special nonprofit or charitable status (e.g., 501(c)(3) in the USA, registered charity in the UK/Canada/Australia)
- This status often enables donors to receive tax deductions and opens access to grants
- Requirements and processes vary; seek local legal advice

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Regional Considerations

Region	Typical Registration Body	Key Considerations
Europe (EU)	National Registry of Associations or equivalent	GDPR compliance for patient data; some countries require notarised documents
North America	State/Provincial corporate registries + federal tax authority	In the US, state registration + IRS 501(c)(3); in Canada, Corporations Canada or provincial
UK	Charity Commission for England & Wales	Must demonstrate public benefit; annual reporting required
Australia	Australian Charities and Not-for-profits Commission (ACNC)	Governance standards; annual information statements
Asia	Varies widely by country	Some countries have restrictive NGO laws; research local requirements carefully
Latin America	Varies by country	May require government approval; consider partnering with existing medical societies initially
Africa	Varies by country	Consider fiscal sponsorship through an existing organization if registration is complex

TFI Support: TFI can provide guidance from established member organizations that have navigated registration in your region.

9. Organizational Structure

The structure of an NGO depends on its size, mission, and activities. Organizations can start small and grow over time.

Starting Small: Minimum Viable Structure

For new organizations, the essential structure may be as simple as:

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- **A small board of 3–5 committed individuals** (including at least one patient representative and ideally a medical advisor)
- **A Chairperson/President** who leads the organization
- **A Secretary** for administrative tasks
- **A Treasurer** for financial management
- **Volunteers** who can help with events, communications, and outreach

Growing Your Structure

Governing Body / Board of Directors:

Responsible for strategy, planning, and oversight. Members should have relevant expertise (medical, legal, communications, fundraising) aligned with the mission.

Executive Management:

Led by a CEO, or Executive Director, Coordinator, responsible for implementing programmes, managing resources, fundraising, partnerships, and reporting.

Functional Areas (can be committees or departments):

- Programme management (events, webinars, support groups)
- Finance and administration
- Communications and advocacy (website, social media, media relations)
- Fundraising and partnerships
- Education and patient resources (brochure development, translations)
- Research liaison (connecting with medical research community)
- Monitoring and evaluation

Medical Advisory Board

Learning from established TFI member organizations, consider establishing a Medical Advisory Board comprising endocrinologists, thyroid surgeons, and other specialists. This ensures:

- All patient education materials are medically reviewed and accurate
- The organization maintains credibility with healthcare professionals
- Patients can access expert guidance through the organization
- The organization can contribute patient perspectives to clinical research

10. Financing the Organization

Securing funding is one of the main challenges for non-profit organizations. A diversified funding strategy is essential.

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Potential Funding Sources

Funding Source	Description	Examples from Established Orgs
Membership fees	Annual fees from individual or family members	Many TFI member organizations operate fee-paying membership programmes
Individual donors	One-time or recurring donations	Online donation portals, direct mail campaigns
Corporate partnerships	Sponsorships from pharmaceutical or health companies	Some organizations partner with selected sponsors for educational programmes
Government funding	National, regional, or local health grants	Health ministry grants, lottery funding
Trusts and foundations	Grant applications to charitable foundations	Research grants, project-specific funding
Fundraising events	Sponsored walks, galas, challenge events	Many organizations promote challenge events and community fundraising activities
Crowdfunding	Online campaigns for specific projects	GoFundMe, JustGiving, local equivalents
Research funding	EU programmes, national research councils	EU funding programmes, NIH grants
Service fees	Payment for educational events, publications	Webinar series, conference registrations
Community organizations	Local clubs, civic groups, religious organizations	Service club grants, community foundation funding

Best Practices for Financial Sustainability

- **Diversify income streams** — Never rely on a single funding source
- **Build recurring revenue** through membership programmes
- **Maintain transparency** with annual financial reports
- **Establish relationships** with potential funders early
- **Document impact** — Funders want to see measurable outcomes
- **Consider in-kind donations** (pro-bono legal, website hosting, printing services)

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- **Explore partnerships** with medical societies that may share costs for educational events

11. Stakeholders

Internal Stakeholders

- Patients and caregivers (the primary constituency)
- Board members and governance
- Staff and volunteers
- Members

External Stakeholders

- Healthcare professionals (endocrinologists, GPs, thyroid surgeons, nurses, pharmacists)
- Medical and professional societies (ATA, ETA, LATS, AOTA, and national endocrine societies)
- Government and public health institutions
- Pharmaceutical companies and medical device manufacturers
- Research institutions and universities
- Media and journalists
- Other patient organizations (both thyroid-specific and broader chronic disease groups)
- Donors, trusts, and foundations
- International bodies (TFI, WHO, EURORDIS)

Stakeholder Engagement Strategy

- Identify key stakeholders and their interests
- Develop tailored communication for each stakeholder group
- Build formal partnerships with medical societies and healthcare institutions
- Engage media for awareness campaigns
- Maintain regular communication through newsletters, social media, and events
- Report outcomes and impact to all stakeholders annually

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Part 4: Building Your Activities and Resources

12. Core Activities for a Thyroid Patient Organization

Drawing from the experience of established organizations worldwide, a thyroid patient organization should consider developing the following activities:

Patient Education and Information

Disease-specific factsheets and brochures to consider:

- Hypothyroidism (underactive thyroid)
- Hyperthyroidism (overactive thyroid)
- Hashimoto's thyroiditis
- Graves' Disease
- Thyroid Eye Disease (TED)
- Thyroid nodules and goitre
- Thyroid cancer (papillary, follicular, oncocytic, medullary, anaplastic)
- Thyroid conditions in children and adolescents
- Thyroid conditions in pregnancy
- Congenital hypothyroidism
- Iodine deficiency and nutrition
- Thyroid medications and treatments

- Frequently Asked Questions (FAQs) for each major condition
- A regularly updated website with accessible, medically reviewed content
- Webinars and online educational sessions featuring thyroid specialists
- Multilingual resources to serve diverse populations — established TFI member organizations offer materials in many languages

Patient Support

- Peer support groups (in-person and online, including social media groups)
- Helplines or email support staffed by trained volunteers (some TFI member organizations offer 7-day-a-week helplines)
- Medical query service connecting patients with specialist advice (established organizations assist thousands of patients annually)
- Patient forums and online communities
- Patient stories and shared experiences to reduce isolation
- Support for carers and family members

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Awareness and Advocacy

- Annual awareness campaigns (International Thyroid Awareness Week, late May)
- "Raise Your Voice for Thyroid" type campaigns
- Engagement with policymakers for better thyroid care policies
- Media outreach (press releases, media interviews, social media campaigns)
- Screening programmes promoting routine thyroid function testing
- Collaboration with medical societies on clinical guidelines that incorporate patient perspectives

Events and Community Building

- Public education meetings with medical experts
- Annual patient conferences or forums
- Fundraising events (challenge events, galas, community runs)
- World Thyroid Day / Thyroid Awareness Week activities
- Webinar series on specific topics

13. Developing Patient Education Materials

Principles for Effective Materials

Based on best practices from established TFI member organizations:

1. Medical accuracy: All materials should be reviewed and endorsed by qualified medical professionals

2. Plain language: Write at a reading level accessible to the general public (aim for 6th–8th grade reading level)

3. Culturally adapted: Consider local healthcare systems, and cultural attitudes to health

4. Multilingual: Translate materials into major languages of your target population

5. Evidence-based: Cite reputable sources and keep information current with latest medical guidelines

6. Patient-centred: Include patient perspectives, stories, and practical tips alongside medical information

7. Actionable: Include clear guidance on what patients should do (e.g., "Talk to your doctor about...")

8. Accessible: Offer materials in multiple formats — web pages, downloadable PDFs, print-ready formats, large text versions

9. Branded: Use consistent visual identity to build recognition and trust

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Material Formats to Consider

Format	Purpose	Notes
Brochures / leaflets	Clinic waiting rooms, events, community outreach	TFI member organizations offer brochure topics
Factsheets (1–2 pages)	Quick reference on specific conditions	Ideal for translation and distribution
Postcards	Brief awareness messages, screening reminders	Eye-catching design for maximum impact
Flyers	Event promotion, awareness campaigns	Community boards, pharmacies, GP surgeries
Booklets / guides	In-depth disease information	TFI member organization handbooks are a good model
Newsletters	Regular member communication	Quarterly newsletters published by TFI member organizations
Posters	Clinic and community display	Symptom checklists, awareness messages
Videos / webinars	Visual education, specialist Q&A	TFI member organizations host regular webinars
Infographics	Social media, quick visual summaries	Shareable awareness content
Website content	Comprehensive, searchable resource library	All major organizations maintain extensive websites

Key Content Areas for Disease-Specific Materials

For each condition (Hypothyroidism, Hyperthyroidism, Thyroid Cancer, etc.), materials should cover:

- **What is it?** — Clear, simple explanation of the condition
- **Who is affected?** — Prevalence, risk factors, demographics
- **Signs and symptoms** — What to look out for
- **Diagnosis** — What tests are used, what to expect
- **Treatment options** — Medications, surgery, other therapies, lifestyle modifications
- **Living with the condition** — Daily management tips, mental health considerations
- **When to seek help** — Red flags and when to contact a healthcare provider

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- **Resources** — Where to find more information, support groups, specialist directories

14. Online Presence and Communication

An effective online presence is essential for outreach and engagement. In today's digital environment, your website and social media channels may be the first point of contact for newly diagnosed patients seeking information.

Website

- Create a clear, professionally designed website with easy navigation
- Organize content by condition / topic (follow the models of established TFI member organizations)
- Ensure the site is mobile-responsive and accessible (WCAG compliance)
- Include a search function for easy resource discovery
- Provide downloadable resources (PDFs, factsheets)
- Feature patient stories and testimonials
- Maintain a news/blog section for updates
- Include clear contact information and referral pathways

Social Media

- Establish profiles on platforms relevant to your target audience (Facebook, Instagram, X, LinkedIn, YouTube, TikTok)
- Share educational content, patient stories, and awareness messages regularly
- Create or join patient support groups (Facebook groups are widely used by thyroid patient organizations)
- Use hashtags related to thyroid awareness to increase visibility
- Engage with followers by responding to comments and messages
- Share content from TFI and partner organizations

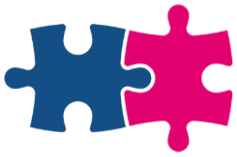
Newsletter / Email Communication

- Build an email list of members, supporters, and interested healthcare professionals
- Send regular newsletters (monthly or quarterly) with:
    - Latest thyroid health information
    - Organization news and events
    - Patient stories
    - Fundraising updates
    - Research highlights

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Media Relations

- Develop relationships with health journalists
- Issue press releases around awareness events and milestones
- Offer spokesperson availability for thyroid-related news stories
- Maintain a media kit with key facts and organizational information



Part 5: Connecting with the Global Community

15. Joining Thyroid Federation International

TFI provides valuable support to emerging thyroid patient organizations:

- **Mentorship** from established member organizations
- **Guidance** on organizational setup, governance, and best practices
- **Networking** with medical professionals and researchers
- **Global visibility** and credibility through TFI membership
- **Activities** on international awareness days

To apply for TFI membership, visit thyroid-federation.org or contact TFI directly. Membership applications are available for both patient organizations and affiliated members.

16. Collaborating with Medical Societies and Alliances

Successful thyroid patient organizations build strong relationships with medical and professional societies. Key potential partners include:

- National endocrine / thyroid societies in your country
- Regional thyroid organizations (e.g., ETA in Europe, LATS in Latin America, AOTA in Asia-Oceania)
- Alliances for thyroid patient education, which bring together multiple patient organizations to pool resources and amplify their collective voice
- General chronic disease patient networks (e.g., EURORDIS for rare diseases)
- International bodies: the WHO

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Part 6: Quick-Start Checklist

Getting Started: Your First 12 Months

Months 1–3: Foundation

- ☐ Identify 3+ founding members with complementary skills
- ☐ Define your vision, mission, and initial goals
- ☐ Research legal requirements for nonprofit registration in your country
- ☐ Contact TFI for guidance and explore membership
- ☐ Identify potential medical advisors
- ☐ Draft your founding documents (constitution/bylaws)

Months 3–6: Establishment

- ☐ Legally register the organization
- ☐ Apply for charitable/tax-exempt status (if applicable)
- ☐ Open a bank account
- ☐ Create a basic website and social media profiles
- ☐ Develop your first patient education materials (start with 2–3 key fact sheets)
- ☐ Recruit initial volunteers

Months 6–9: Launch and Outreach

- ☐ Launch your website and social media presence publicly
- ☐ Host your first public event or webinar
- ☐ Begin building relationships with local endocrinologists and healthcare providers
- ☐ Distribute materials to local clinics, hospitals, and pharmacies
- ☐ Begin membership recruitment
- ☐ Apply for initial funding or grants

Months 9–12: Growth and Sustainability

- ☐ Evaluate your first activities and gather patient feedback
- ☐ Expand your resource library (additional factsheets, brochures)

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☐ Plan for annual awareness events (e.g., International Thyroid Awareness Week)

☐ Develop a fundraising strategy for the coming year

☐ Submit your TFI membership application (if not already done)

☐ Set goals and budget for Year 2

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Appendices

Appendix A: Key Thyroid Disease Facts for Awareness Materials

- Thyroid diseases affect more than 200 million people worldwide
- Up to 60% of those with thyroid disease may be unaware of their condition
- Women are 5–8 times more likely than men to develop thyroid problems
- Hypothyroidism (underactive thyroid) is the most common thyroid disorder
- Thyroid disease can affect people of all ages, including newborns and children
- Early diagnosis and proper treatment allow most thyroid patients to lead normal, healthy lives
- A simple blood test (TSH) can detect most thyroid disorders
- Iodine deficiency remains a significant cause of thyroid problems in many parts of the world
- Thyroid cancer is the most common endocrine malignancy but has a very high cure rate when detected early
- Autoimmune thyroid diseases (Hashimoto's and Graves') are among the most common autoimmune conditions

Appendix B: Key Organizations and Resources

Organization	Website	Focus
Thyroid Federation International (TFI)	thyroid-federation.org	Global patient organization network
Patient education libraries	eurothyroid.com	European medical and professional society
Membership and newsletter models	—	Latin American medical and professional society
Helplines and support services	—	Asia-Oceania medical and professional society
Community education programmes	eurordis.org	European network for rare disease patient organizations
Online patient communities		
European Thyroid Association (ETA)	eurothyroid.com	European medical society
Latin American Thyroid Society (LATS)	—	Latin American medical society

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Appendix C: Glossary of Common Thyroid Terms

Term	Definition
Hypothyroidism	A condition where the thyroid gland does not produce enough thyroid hormone (underactive thyroid)
Hyperthyroidism	A condition where the thyroid gland produces too much thyroid hormone (overactive thyroid)
Hashimoto's thyroiditis	An autoimmune condition that is the most common cause of hypothyroidism
Graves' Disease	An autoimmune condition that is the most common cause of hyperthyroidism
Goitre	An enlargement of the thyroid gland
Thyroid nodule	A lump or growth in or on the thyroid gland
Thyroiditis	Inflammation of the thyroid gland
TSH (Thyroid Stimulating Hormone)	A hormone produced by the pituitary gland that stimulates the thyroid; used as the primary screening test
T4 (Thyroxine)	The main hormone produced by the thyroid gland
T3 (Triiodothyronine)	The active form of thyroid hormone; converted from T4 in the body
FNA (Fine Needle Aspiration)	A biopsy procedure used to evaluate thyroid nodules
RAI (Radioactive Iodine)	A treatment used for hyperthyroidism and certain thyroid cancers
Levothyroxine	The standard medication used to treat hypothyroidism
Thyroid Eye Disease (TED)	An autoimmune condition affecting the eyes, often associated with Graves' Disease
Thyroid cancer	Cancer arising from the thyroid gland; types include papillary, follicular, oncocytic, medullary, and anaplastic

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This toolkit provides a structured roadmap for establishing and sustaining a thyroid patient organization, combining legal, strategic, and patient-centred perspectives. It was developed by TFI with input from member organizations worldwide.

For the latest version and additional resources, visit: thyroid-federation.org

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