

#### Introduction

The FIN resources guide is a practical guide for anyone active in the Fabry community and broader patient advocacy. The guide helps member organizations quickly find the right digital tools, software, and training to strengthen their operations: from communication and team organization to fundraising and patient education. All tools listed have been chosen because they are relevant, user-friendly, and often available for free or at a non-profit discount.

This guide is divided into following categories:

- 1. Software & tools for non-profits
- 2. Communication & design
- 3. Training & learning platforms
- 4. Project & team management
- 5. Social media & community building
- 6. Data & surveys
- 7. Events & online meetings

The guide is updated every six months to ensure that members always have the most up-to-date information.



## 1. Software & tools for non-profits

This category brings together essential software that facilitates the daily operations of patient organizations: collaboration, documents, email, CRM, and fundraising. Many tools offer free or discounted nonprofit rates.

	Tool	Description	Price/Non- profit discount	Website
Google Workspace for Nonprofits  M 31	Google Work- space for nonprofits	Email, Drive, Docs, Meet in one secure cloud environment	Free basic + discounts on premium	https://google.com/nonprofits





Office 365 for non profits	Microsoft 365 nonprofit	Office suite (Word, Excel, Teams, Outlook) with collabora- tion tools	Free and paid packages with high discounts	https://microsoft.com/nonprofits
salesforce nonprofit success pack	Sales- force nonprofit success pack	CRM for member, donor, and relationship manage- ment	Heavily discounted packages	https://salesforce.org/nonprofit
zeffy≌	Zeffy	Donations and ticketing without transaction fees	100% free (tip model)	https://zeffy.com/



<b>Givebutter</b>	Givebutter	Fundraising + event ticketing + donation pages	Free/low cost	https://givebutter.com
mailchimp	Mailchimp (for non- profits)	Newsletters and email campaigns with automation	Discount for non-profits	https://mailchimp.com
ZOOM techsoup	Zoom via TechSoup	Reliable virtual meetings and webinars	Discount via TechSoup	https://techsoup.org

## **♥** TIP from FIN

Use TechSoup Belgium as a starting point to apply for discounts and licenses for non-profits: <a href="https://techsoup.be">https://techsoup.be</a>

# 2. Communication & design

This category contains tools for designing visual content, branding and campaign materials.

	Tool	Description	Price/Non- profit discount	Website
Canva	Canva for nonprofits	Quickly create graphics, presentations, and social media posts Easy to use	Free PRO- version for certified nonprofits	https://www.canva.com/canva- for-nonprofits/
SCAN ME	QR-code generator	QR codes for flyers, posters, programs, and registration	Free and paid packages with significant discounts	https://qrcodecreator.com https://qrfy.com https://www.qr.io and many more



## 3. Training & learning platforms

Training and knowledge platforms covering nonprofit work, advocacy and health communication.

Tool	Description	Price/ Non-profit discount	Website
Nonprofit Ready	Free management training courses for nonprofit skills	Free	https://nonprofitready.org
Coursera for Nonprofits (via TechSoup)	Online courses (management, data, communication)	Free/discount via TechSoup	via <a href="https://techsoup.org">https://techsoup.org</a>
edX	University courses (public health, advocacy, digital tools)	Free/paid	https://edx.org/
TechSoup Courses	Broud resource hub with software offers and courses	Discount	https://techsoup.org



The Advocacy Accelerator	Training & resources for effective patient advocacy	Variable	https://advocacyaccelerator.us
Patient Advocacy Academy	Especially for patient representation	Variable	https://patientadvocacy.academy
Erdera	European learning hub, raising raredisease knowhow	Variable	https://erdera.org
EURORDIS Open Academy	European training for rare diseases advocates	Often sponsored	https://openacademy.eurordis.org
EUPATI Learning	Patient eduction on medicin-R&D.	Free/paid	https://learning.eupati.eu
EUCAPA	Capacity building for patient representatives	Variable	https://eucapa.eu
ERN Metab Education	Education on metabolic disorders	Variable	https://metab.ern-net.eu/



EIT Health Academy	Innovation and healthcare training	Variable	https://eithealth.eu/
Learn.RareDiseases	Various training courses on rare diseases	Variable	https://learn.rarediseases.org
EU patient capacity building programme	Lead patient advocacy in Europe	Variable	https://www.eu-patient.eu/



# 4. Project & team management

Collaboration, task planning and progress tracking, ideal for volunteer and core teams.

[ <u>2</u> ] <u>288</u>		Tool	Description	Price/ Non-profit discount	Website
	# slack	Slack for nonprofit	Team communication, channels per project /workgroup	Free or significant discount	https://slack.com/nonprofits
	asana	Asana	Project planning, deadlines, checklists	Discount for nonprofit	https://asana.com
	<b>□</b> Trello	Trello	Visual boards (Kanban) for tasks and project management	Discount for nonprofit	https://trello.com





Microsoft Teams and Google Drive are also suitable for project and team management and are part of Microsoft 365 and Google Workspace – check Software & tools for non-profits.



## 5. Social media & community building

Social media accounts, inspiring podcasts and communities to follow for information, updates, for networking and campaign inspiration.

#### Organizations, associations and federations

(III/GH)	Platform	Link	What?
	Instagram	@eurordis	Rare disease advocacy across Europe
@globa		@globalgenes	Awareness, community building & research updates
	Instagram	@nonprofitready	Tips & training for nonprofit staff





#### Patient and advocacy influencers (for inspiration – check relevance per target group)

Platform	Link
Instagram	@chronicillnesswarrior
Instagram	@rarediseaseunited
Instagram	@JIREH



Instagram	@friendswithfabry
Instagram	@ladyfabryinternacional
Instagram	@morethanmyfabry
Instagram	@aktivmitfabry
Instagram	@fabryyouthsupport



## Podcasts

Title	Description
Rare disease connection	Patient stories and expert interviews
Patient Empowerment Network Podcast	Health literacy & self-advocacy
Global Genes RARECast	Community & research in rare diseases
Nonprofit Jenni Show	Management tips for small to mid-sized nonprofits
The Charity CEO Podcast	Leadership in the nonprofit sector
The Fabrycast	Fabry Canada
Patienstoriespodcast	Personal experiences of patients with genetic conditions



# 6. Data & surveys

Forms, surveys and data tools for feedback, registration and evidence building.

	Tool	Description	Price/ Non-profit discount	Website
<b>%</b> Jotform	Jotform (nonprofit)	Forms & surveys for patient feedback, registration	Discount for nonprofit	https://jotform.com/nonprofit
SurveyMonkey®	SurveyMonkey	Surveys with logic/reporting	Discount for nonprofit	https://surveymonkey.com
Data Saves Lives	Data Saves Lives Toolkit	Practical toolkit for datadriven health	Free	https://datasaveslives.eu/toolkit



# 7. Events & online meetings

Interactive tools for webinars, online meetings, virtual events and workshops.

P P P RI EVENTS	Tool	Description	Price/ Non-profit discount	Website
ZOOM techsoup	Zoom via TechSoup	Reliable virtual meetings and webinars	Discount via TechSoup	https://techsoup.org
slido	Slido live Q&A	Polls & word clouds	Freemium/paid	https://slido.com
Kahoot!	Kahoot!	Interactive quizzes and educational sessions	Freemium/educational	https://kahoot.com



zeffy≌	Zeffy	Donations and ticketing without transaction fees	100% free (tip model)	https://zeffy.com/
<b>Givebutter</b>	Givebutter	Fundraising + event ticketing + donation pages	Free / low cost	https://givebutter.com