



ANNUAL REPORT 2024/2025

YOUR SUPPORT. OUR VOICE. SHARED IMPACT.



A WORD FROM THE FOUNDER & CEO

Dear supporters and Young Tongues community,

This year has been one of meaningful growth, deep learning, and extraordinary resilience. As a young and fast-developing charity, we have navigated both momentum and challenges, like expanding our global reach while strengthening the foundations that will carry us into the future.

Despite limited resources and the ongoing demands of leading a start-up charity, our commitment to young people living with tongue cancer has remained unwavering. I am proud of what we've achieved together. Every shared story, every peer support exchange, every clinician we've inspired, every researcher we've influenced, and every policy conversation we've contributed to is a testament to the power of our community.

This year, we supported hundreds of young patients navigating one of the most isolating cancers. We grew our digital support groups, expanded in-person gatherings, strengthened our global network, shaped research proposals, delivered speeches to healthcare leaders across Europe, and amplified patient voices where they are needed most.

Our mission is simple: ensure no young adult faces tongue cancer alone and ensure our voices drive change in diagnosis, care, research and policymaking.

This report captures our progress, our challenges, and our hopes for the future.

Thank you for standing with us as we build something vital, meaningful and deeply human.

A handwritten signature in black ink, appearing to be 'BF' with a stylized flourish.

BARBARA FOUNTAIN
CEO & FOUNDER

EXECUTIVE SUMMARY

In 2024/2025, Young Tongues grew from a courageous idea into a global movement. We strengthened our core support services, reached new professional audiences, expanded research collaborations, and made progress in policy campaigning.

We also invested in governance, safeguarding, financial processes, and digital infrastructure laying the groundwork for long-term sustainability. This year, we:

- Supported a rapidly growing global community of young patients
- Delivered monthly virtual meet-ups and new in-person gatherings
- Released new podcast episodes featuring patients, clinicians and researchers
- Spoke at international conferences including ECHNO 2025
- Joined national advocacy efforts influencing NHS planning
- Collaborated with universities, hospitals and scientists across the UK, Europe, Australia and the US

THE NEED

Tongue cancer in young adults is rising sharply. Research published in Oral Oncology, showed a significant increase in the incidence of tongue cancer in people under 45, particularly in young women where the incidence has risen by a staggering 385% over 32 years. Yet younger patients still face:

- Frequent misdiagnosis
- Long delays to referral
- Age-inappropriate support information
- Limited support from peers their own age
- Life-altering long-term effects
- A lack of research reflecting their lived experience

Young Tongues is the only organisation worldwide dedicated exclusively to supporting young people diagnosed aged 18–64 facing tongue cancer. We exist to fill urgent gaps in support, advocacy, research engagement, and awareness.

OUR YEAR IN IMPACT



Patient support group
Supporters group
Young Tongues Lifers

16,757
comments
made



1,453
POSTS

800+

18-64 year old tongue
cancer patients from
around the world



50

PODCAST
EPISODES



IN 30+

4,426 DOWNLOADS



10

VIRTUAL
MEET-UPS



2

IN-PERSON
MEET-UPS





Diagnose Sooner

Champion earlier recognition and referral of tongue cancer in younger patients.



Support Smarter

Deliver care and peer support that reflects the unique needs of younger adults.



Change the System

Shape policy and practice to better protect, treat and empower young patients.



Lead with Lived Experience

Ensure patient voices guide research priorities from start to finish.

Spotlighted the issue on the Eastman Dental Podcast and in The Royal College of Surgeons Edinburgh magazine ("Don't Ignore the Signs").

Contacted 26 dental bodies in the UK to build relationships and explore collaborations.

Shared real-world delay stories in every talk, shifting "rare anecdote" to "urgent pattern."

Presented the Young Tongues story along side the Make Sense Campaign at ECHNO 2025 in Amsterdam.

Spoke at BISOM and delivered a CPD webinar for BADT.

Reached out to 50 surgeons, oncologists and allied HCPs across four continents, opening dialogue on best practice.

Joined key national coalitions to ensure a united voice across the cancer community. These partnerships have enabled us to support larger campaigns.

Submitted official responses to the UK Government's calls for evidence on both the NHS 10-Year Plan and the National Cancer Plan, ensuring the specific needs and lived experiences of our community are reflected.

Served as co-applicants on two studies focused on diagnostic innovation for tongue cancer.

Contributed lived-experience insight through our Patient Expert Group to grant led by the Garvan Institute.

Awarded a £1,000 grant to help launch the National Head & Neck Cancer Audit Feasibility Study, advocating for the return of this critical NHS data collection.

IMOGEN

When Imogen from England was diagnosed with tongue cancer at 27, she quickly learned that even excellent medical care cannot replace the comfort of lived experience. “I had an incredible medical team,” she explains, “but there’s no substitution for hearing directly from people who’ve walked this path before you.”

She joined Young Tongues just as she was finishing treatment – at a moment when she’d lost faith in her own recovery. Having had almost her entire tongue removed, Imogen believed she would never eat solid food again. “I’d pretty much given up on the idea,” she says. But through the group’s guidance, practical tips, and stories of others who had rebuilt their lives, she slowly began to try again. “Thanks to the support of Young Tongues, I can now eat anything – including steak.”

For Imogen, the group’s impact reached far beyond physical recovery. It became a space where she felt encouraged, reassured, and understood. “Shared experiences are everything,” she reflects. “Sometimes all you need is to know someone else has been through this too.”

Today, Imogen is not only thriving after treatment – she has achieved a major milestone: earning her PhD. Giving back to others in the group has become part of her healing. “Being able to help others has helped me reconcile what happened to me. The most important thing Young Tongues gave me is hope.”





SIMONA

When Simona from Switzerland was diagnosed with tongue cancer at just 26 years old, even her medical team struggled to comprehend it. “It’s very unusual for someone your age to develop this type of disease,” they told her. “It doesn’t match your age or lifestyle. You’re far too young for this.”

She had never smoked, rarely drank alcohol, and had none of the typical risk factors. Yet the diagnosis came and with it, a profound sense of loneliness. Simona didn’t know anyone her age with a tumour in the mouth. Not even her clinicians had experience treating young patients like her. “I felt alone, strange... almost like an alien,” she wrote. “Not being able to talk to anyone who understood was the hardest part.”

Determined to find connection, she searched for support groups in Switzerland but found none for young adults with head and neck cancers. Eventually, she discovered Young Tongues and everything shifted. She found peers around the world who understood her fears, her treatments, her questions, and the invisible weight of recovery. “They gave me so much, especially the comforting feeling of no longer being alone.”

Simona remained an active, warm, and compassionate member of our community.

In August 2024, Simona sadly passed away. Her loss is felt deeply by all of us. We are profoundly grateful to her family, who chose to honour her memory by supporting Young Tongues through fundraising in her name. Their generosity ensures that Simona’s legacy continues to support others who feel isolated by this disease.



MUS

When Mus from England talks about tongue cancer, he doesn't soften the truth. "Tongue cancer is one of the most brutal types of cancer," he says. "It affects your speech. It impacts your ability to eat and swallow."

Surgery brought swelling and visible changes, and radiotherapy layered on its own relentless challenges: sore throats, ulcers, constant coughing, a dry mouth combined with thick, sticky mucus that was impossible to spit out. The physical toll was immense, but the emotional isolation was just as heavy.

"Going through all of that alone..." Everything shifted when he found Young Tongues.

Through the charity, Mus connected with people who had lived through the same treatments and come out the other side. At meet-ups he began hearing the voices of people months, years, or even decades ahead of him. "They can tell you that things will get better," he says. "Sometimes that's all you need to hear."

For Mus, that simple reassurance changed everything. The community gave him understanding, hope, and the powerful knowledge that healing is not only possible, but shared.

"That's why Young Tongues is so important," he says. "No one should have to go through this alone."

KELLY

When Kelly from the USA was diagnosed with tongue cancer at 35, she quickly discovered how isolating the experience could feel. Even surrounded by supportive people, she longed for connection with others who truly understood what she was going through. That changed when she found Young Tongues. “It kept me positive when I was feeling low,” she says. “It’s given me an amazing group of people to talk with who understand what I am going through.”

Early recovery brought practical challenges and the group became a lifeline. Members shared advice that helped her manage everything from an itchy neck dissection site to navigating eating again after treatment. “And so much more,” she adds. Each tip, each message, each shared experience helped steady the path forward.

Kelly joined the virtual meet-ups and immediately felt the impact on her emotional wellbeing. “They kept me positive and gave me amazing friends to lean on,” she explains. What meant the most was the shared experience: hearing others describe feelings, fears and victories that mirrored her own.

She also found comfort in the Young Tongues podcast. Listening to episodes helped her feel less alone in her own journey. “Basically all of them resonated,” Kelly says. “I feel like I’m with them and want to join the conversation.”

Today, Kelly describes Young Tongues as the community that helped her find understanding, hope, and genuine friendship at one of the hardest moments in her life. “They’re always there to help,” she says and that connection continues to carry her forward.



YOUNG TONGUES PODCAST

Another place where we've truly found our voice – quite literally – is through the Young Tongues Podcast, which Barbara co-hosts with the brilliant Jamie Powell.

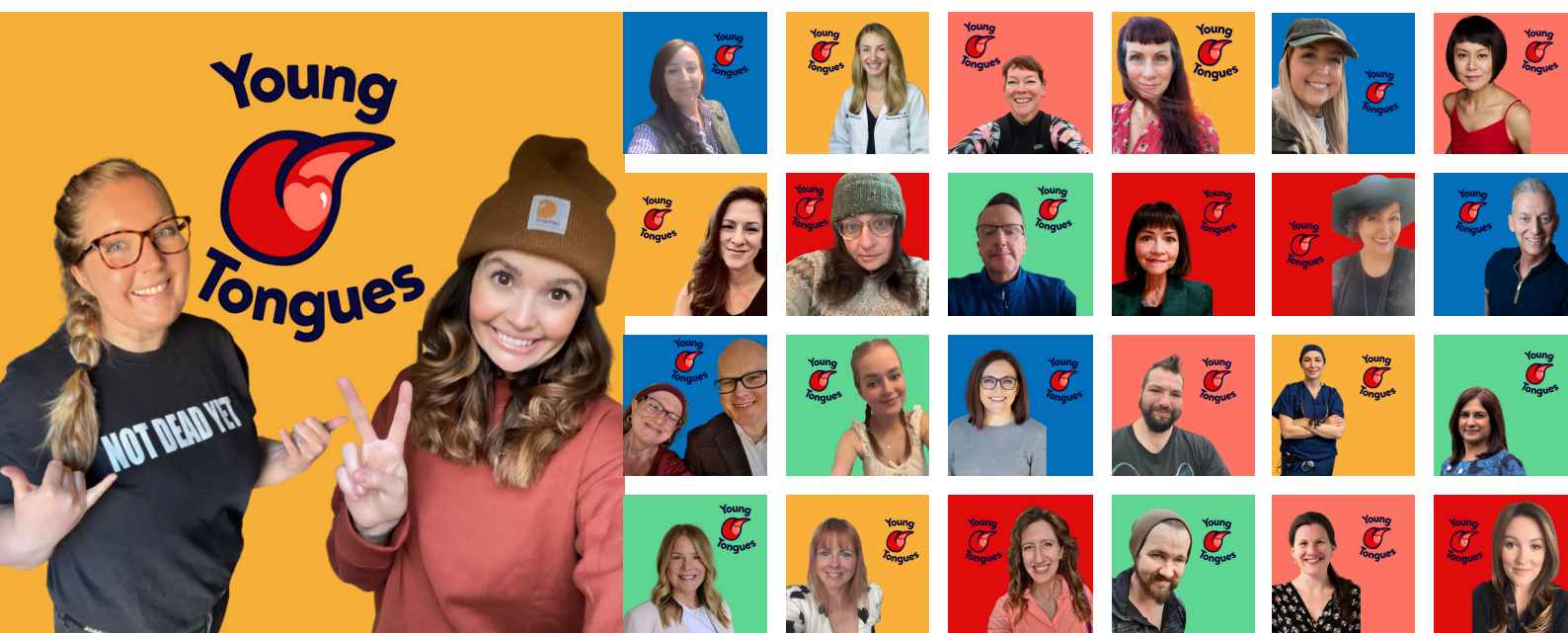
What began as a simple idea to open up more honest conversations has grown into a powerful platform for storytelling, connection, and advocacy. This year, we reached an incredible milestone: 50 recorded episodes, each capturing the lived realities, humour, fears, resilience and expertise that shape life during and after tongue cancer.

In 2024/2025 we launched Series 2, expanding the range and depth of the conversations we bring to our community. Episodes featured fellow Young Tongues sharing their personal journeys – from diagnosis to recovery and everything in between – alongside clinicians, therapists, and researchers offering insight into the medical and emotional realities of treatment.

What's made the greatest impact, however, is how far these voices have travelled. With 4,426 downloads across more than 30 countries, the podcast has become a lifeline that reaches far beyond any physical support group. Somewhere in the world, at any given moment, someone is pressing play at exactly the time they need to feel seen, heard, and less alone.

Looking ahead, we hope to further professionalise the podcast for Series 3, enhancing both production quality and reach, with the aim of attracting sponsorship to help us make that vision a reality.

The podcast has become more than a series of episodes: it's a growing archive of lived experience, a space for truth-telling, and a testament to the power of community voices shaping change.



BOARD OF TRUSTEES 2024/2025



Barbara Fountain
CEO & Founder
Tongue Cancer Patient



Laura Marston
Chair
Tongue Cancer Patient



Hannah Thorpe
Treasurer
Tongue Cancer Patient



Susan Smith
Trustee
Tongue Cancer Patient



Kate Hall
Trustee
Tongue Cancer Patient



Jake Ahmed
Trustee
ENT Surgeon

A special THANK YOU to
fellow Young Tongues
Natalie and Kelly for
supporting our secretariat!



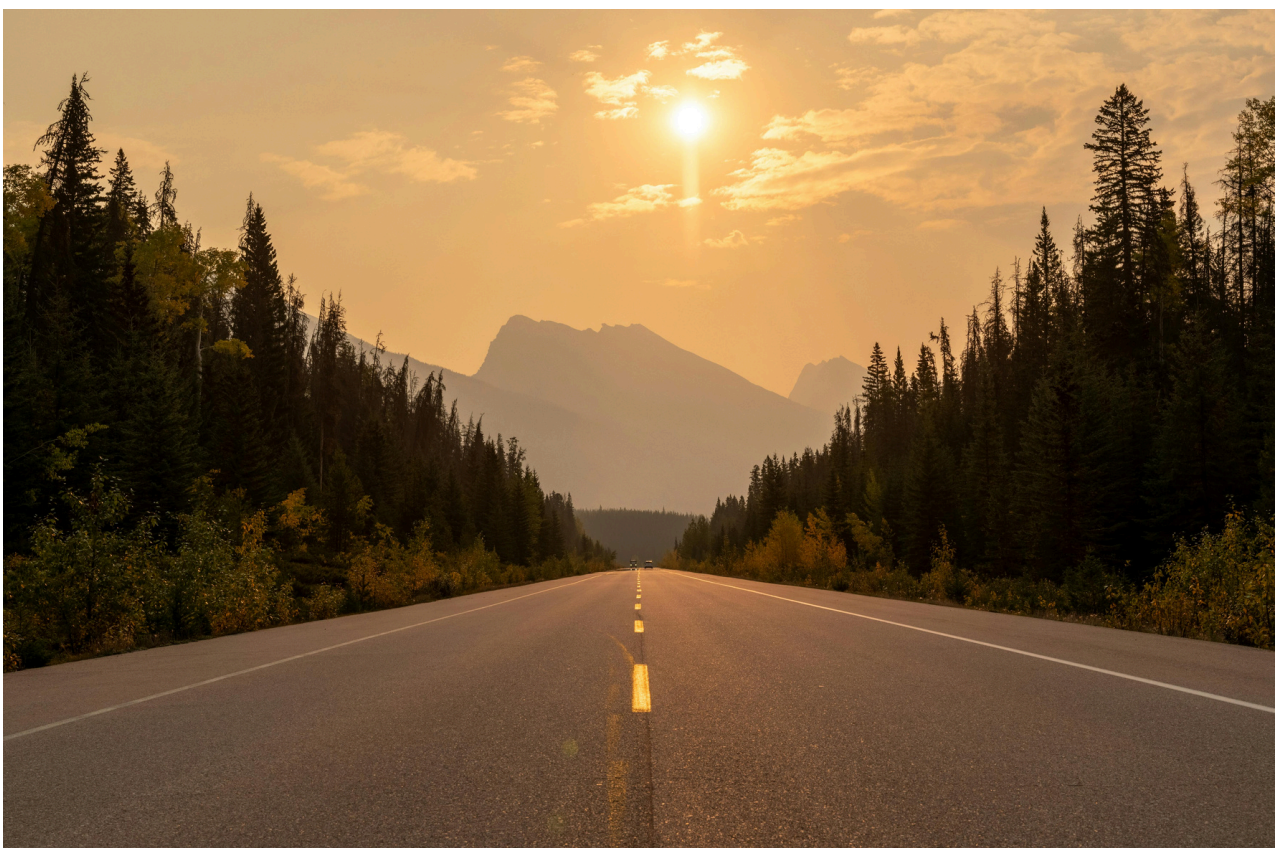
THE ROAD AHEAD

As we look ahead to 2025/2026, our focus is clear: strengthening our foundations, widening our impact, and ensuring that every patient who turns to us receives safe, high-quality, and life-changing support. Over the past year, we have proven what can be achieved with limited resources and extraordinary community commitment. Now, we must build on this momentum and take the next essential steps in our growth.

A key priority for the coming year will be the development of a robust 2025/2026 Budget and Fundraising Strategy. To sustain and expand our services, we must increase our annual fundraising target to £60,000 – a critical investment in keeping patients supported, volunteers empowered, and the organisation resilient.

We will also complete the full implementation of our Safeguarding Policy across all activities, launch our new Volunteer Recruitment Programme, and continue to expand our global peer support network, in-person meet-ups, and professional partnerships.

Most excitingly, we will begin work on two major developments that will transform the support we provide the Young Tongues Hub and the Young Tongues Patient Insight Platform.



THE YOUNG TONGUES HUB

In the year ahead, we will begin developing one of our most impactful and ambitious initiatives: the Young Tongues Patient Support Hub: a purpose-built digital space designed to transform how younger adults access support, information, and community throughout their tongue cancer journey.

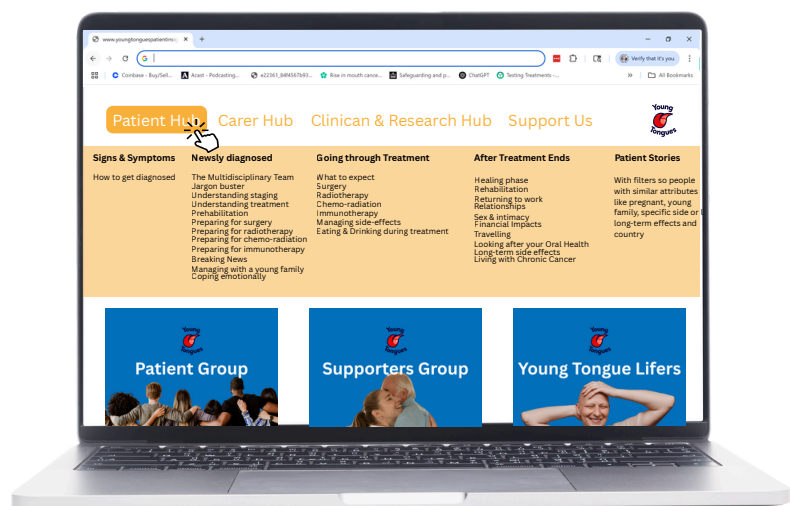
Over time, our Facebook groups have accumulated an extraordinary depth of shared knowledge. Hundreds of young patients have offered practical advice, emotional support, treatment insights, and lived experience that simply cannot be found elsewhere. But this wealth of information can be difficult to navigate, overwhelming to search, and almost impossible for newly diagnosed patients to access at the moment they need it most.

The Support Hub will change this.

Beginning next year, we will build a new Young Tongues website featuring a centralised, searchable hub that places younger patient experiences at the heart of every page. Content will be written in clear, human language, shaped by real patients and carers, and then reviewed by clinicians to ensure accuracy, safety and trust.

The Hub will be structured around the patient journey – from early symptoms and diagnosis, through surgery and treatment, to life beyond cancer and long-term survivorship. It will offer guidance on the topics younger patients repeatedly tell us they cannot find elsewhere: pushing for referrals, navigating fertility, coping with body image changes, returning to work, managing relationships, rebuilding confidence, and even dating after treatment.

This project will bring together patients, carers, clinicians, and researchers to create a resource that is honest, compassionate, and genuinely useful. Their combined expertise will allow us to turn lived experience into life-changing support.



THE YOUNG TONGUES PATIENT INSIGHT PLATFORM

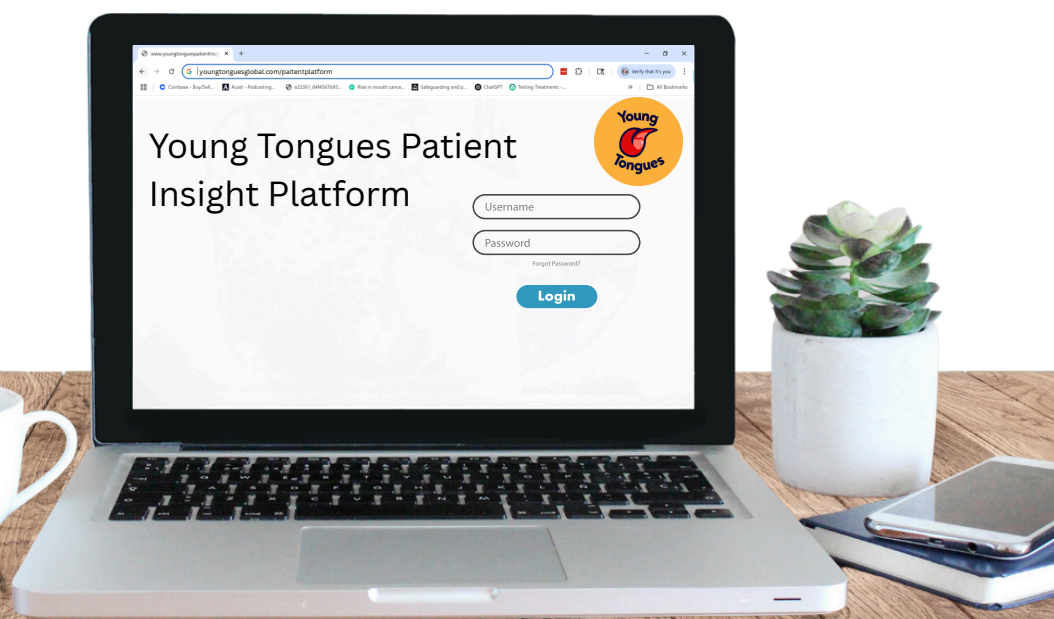
One of the most significant challenges facing younger adults with tongue cancer is that their experiences are largely invisible in the data that informs research, treatment pathways, and national cancer strategies. Their stories exist – powerful, detailed, often life-changing – but they rarely make it into the evidence that shapes care.

In 2025/2026, we will begin addressing this gap through the development of the Young Tongues Patient Insight Platform: a global, consented data initiative designed to bring younger patients' voices into the centre of research, clinical decision-making, and policy.

The Insight Platform will become the first international, longitudinal dataset dedicated exclusively to adults aged 18–64 with tongue cancer. It will capture their journeys in real time – from symptoms and diagnostic delays, through treatment and side effects, to rehabilitation, late effects, quality of life, and long-term survivorship. No existing dataset reflects this perspective or demographic with accuracy or depth.

The project is being co-designed with clinicians, researchers, data specialists, and our community, ensuring it is robust, inclusive and globally relevant. As it develops, the platform will help close long-standing knowledge gaps, accelerate research, and strengthen the case for better services and policies.

The Young Tongues Patient Insight Platform has the potential to reshape the future of tongue cancer care – ensuring younger patients are finally seen, counted, and heard where it matters most.



FINANCIAL OVERVIEW

2024/2025

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
Community Fundraising	26,776	-	-	26,776	2,680
Donations	1,650	-	-	1,650	-
Grant Income	15,000	-	-	15,000	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	43,426	-	-	43,426	2,680
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	43,426	-	-	43,426	2,680
A3 Payments					
Fundraising Costs	439	-	-	439	24
Digital Marketing	2,520	-	-	2,520	286
Website	122	-	-	122	242
Networking	22	-	-	22	-
Insurance	310	-	-	310	310
IT Software & Consumables	271	-	-	271	-
Research Grants	1,200	-	-	1,200	-
Freelancer Costs	14,994	-	-	14,994	-
Training	5,771	-	-	5,771	-
Travel	490	-	-	490	-
Bank Charges	20	-	-	20	10
Sub total	26,159	-	-	26,159	872
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	26,159	-	-	26,159	872
Net of receipts/(payments)	17,267	-	-	17,267	1,808
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	-	-	-	-	-
Cash funds this year end	17,267	-	-	17,267	1,808

THANK YOU

Everything in this report – every support group message, every podcast episode, every research conversation, every moment of connection – exists because of people who chose to stand alongside Young Tongues this year.

We would like to extend our heartfelt thanks to everyone who has supported Young Tongues during 2024/2025.

To the **young patients and supporters** who trusted us with your stories, your questions, your fears and your hope – thank you. Your openness, courage and generosity in sharing lived experience are the foundation of everything we do. You are the reason Young Tongues exists, and your voices continue to shape our direction, our priorities and our ambition.

To our **volunteers**, who give their time, skills and compassion so freely – from hosting meet-ups and creating content, to supporting fundraising and research – thank you. Your commitment makes our work possible and strengthens our community in ways that cannot be measured.

To our **trustees**, thank you for your guidance, challenge, and belief in this charity as it continues to grow. Your oversight and support have been essential as we've built the foundations for long-term sustainability.

To our **fundraisers and donors**, whether you took on a challenge, marked a special occasion, donated quietly, or fundraised in memory of someone you love – thank you. Your generosity directly impacts young people navigating one of the most difficult periods of their lives.

To our **clinical, research, and charity partners**, thank you for listening to patient voices, for collaborating with openness, and for recognising the importance of age-appropriate care and insight.

And finally, to everyone who has shared our work, amplified our message, attended an event, or simply reminded someone they are not alone – thank you.

Young Tongues is still a young charity, but it is built on an extraordinary community. Together, we are creating connection, understanding, and change – and we are deeply grateful to each and every person who has been part of this journey.³

Your support. Our voice. Shared impact.

Your Support. Our Voice. Shared Impact.

Even though I was lucky to have an incredible medical team, there's no substitution for lived experiences. I have received invaluable advice, support, and guidance from people in the group, and being able to help others now has helped me reconcile what happened to me. The most important thing Young Tongues gave me is hope.

Young Tongues has made a significant difference to my life by providing relevant information and connection to others in similar situations I don't have access to in any other way.

I have felt less alone and now feel a sense of belonging to a community of people who know what it's like first hand. It has introduced me to people from the same country as me who have gone through the same thing which is even more of a sense of community

I'm 25+ years out, and only now finding things out that I should have been told years ago. Unlike happy clappy support groups, with their 'must look on the bright side' toxic positivity, this group gives you actual lived experience, useful advice and support

I found the group before starting treatment and it was an amazing resource. It was always there to support me in difficult times. I could ask anything and get people's real experience. I felt I wasn't alone which was a huge comfort.

It has kept me positive when I was feeling low. It has given me an amazing group of people to talk with who understand what I am going through





CHARITY COMMISSION
FOR ENGLAND AND WALES

Young Tongues CIO

1204866

Receipts and payments accounts

CC16a

For the period
from

01/04/2024



To

31/03/2025

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
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A6 Cash funds last year end	-	-	-	-	-
Cash funds this year end	17,267	-	-	17,267	1,808

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	Current Account	19,075	-	-
		-	-	-
		-	-	-
	Total cash funds	19,075	-	-
	(agree balances with receipts and payments account(s))	Agreement	OK	OK
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets		Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use		Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities		Fund to which liability relates	Amount due (optional)	When due (optional)
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees		Signature	Print Name	Date of approval
			Barbara Fountain	24/12/2025
			Hannah Thorpe	24/12/2025



Section A

Independent Examiner's Report

Report to the trustees

Charity Name
Young Tongues CIO

On accounts for the year
ended

31 March 2025

Charity no
(if any)

1204866

Set out on pages

1 to 2

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended **31/03/2025**.

Responsibilities and
basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent
examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination (other than that disclosed below *) which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

** Please delete the words in the brackets if they do not apply.*

Signed:

Date:

19/12/25

Name:

Nicola Fowler, NJF Accounts Ltd

Relevant professional
qualification(s) or body
(if any):

FCCA CTA

Address:

21 Springfields

Poringland

Section B**Disclosure**

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.