



Trustees' Annual Report Letter

Kleefstra Syndrome UK

Charity Number: 1208059

Reporting Period: 1st January 2025 – 31st December 2025 (2nd year accounts)

Trustees' Annual Report for the Year Ended 31.12.2025

Charity Name: Kleefstra Syndrome UK

Charity Registration Number: 1208059

Reporting Period: 1st January 2025 – 31st December 2025

1. Objectives and Activities

Kleefstra Syndrome UK was established to support families and individuals affected by Kleefstra syndrome — a rare genetic condition with complex needs. The charity aims to:

- Provide information, advice and emotional support to families and carers
- Raise awareness among professionals and the public
- Facilitate connections between families through events and online platforms

All charitable activities are designed to further our aim of ensuring that no family faces the Kleefstra Syndrome journey alone.

2. Achievements and Performance

During this second year as a registered charity, our key achievements include:

- Providing ongoing peer support to families via online communities and one-to-one connections
 - Planning for our 2026 national family conference to be held in July 2026.
 - Fundraising and applying for grants for upcoming national family conference to be held in July 2026
 - Key partner in the international Kleefstra syndrome meetings.
 - Organising local family meet-ups and accessible outings
 - Creating online resources for families and professionals
 - Strengthening our partnerships with researchers and clinicians
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3. Financial Review

The charity's income for the year was under £16,000, derived from individual donations, grants and small fundraising activities. Expenditure was in line with our charitable objectives, including support activities, event planning, and communications including expenditure relating to upcoming national family conference in 2026.

No remuneration was paid to trustees, but some trustees claimed reasonable expenses in line with our financial procedures.

The charity's finances were managed prudently, and we maintain sufficient reserves to meet upcoming planned activities.

4. Structure, Governance and Management

Kleefstra Syndrome UK is a registered charitable trust governed by a Board of Trustees. Trustees are volunteers and meet regularly to oversee strategy, activities, and financial matters.

The charity was formally registered with the Charity Commission on **30 April 2024**, having previously operated as an unregistered voluntary group.

5. Public Benefit Statement

In exercising their duties, the trustees have had due regard to the Charity Commission's guidance on public benefit. The charity's work supports individuals and families affected by Kleefstra Syndrome across the UK and contributes to public awareness and inclusion for people with rare condition.



**STATEMENT OF FINANCIAL ACTIVITIES
INCLUDING INCOME AND EXPENDITURE ACCOUNT**

FOR THE YEAR ENDING 31st December 2025 (period from 1st January 2025 - 31st December 2025)

Balance at Nat West Account 01.01.2025		10434.68
Balance at Paypal 01.01.2025		<u>989.30</u>
Available reserves as at 01.01.2025		11,423.98
INCOME		
Restricted Income:		
Grants	10,000.00	
Unrestricted:		
Subscriptions/Donations	2,528.31	
<u>Fundraising</u>	<u>2,810.65</u>	
	15,338.96	26,762.94
Less Expenditure		
Restricted Expenditure:	0.00	
Unrestricted Expenditure:		
UnreFees (PP)	23.11	
Zoom (NW)	155.88	
Markel Insurance (NW)	134.40	
Conference 2026	928.00	
Website Maintenance	138.24	
Apparel	16.20	
Just Giving	70.00	
<u>Regional Meetings</u>	<u>545.75</u>	
Total expenditure paid out	2,011.58	24,751.36

Balance sheet as at 31 December 2025

	Unrestricted Funds (£)	Restricted Funds (£)	Total (£)
Cash at bank and in hand			
Monies held at NatWest	14,751.36	10,000.00	24,751.36
Monies held at PayPal	0.00	0.00	0.00
Total cash held	14,751.36	10,000.00	24,751.36

Reserves Position

	Unrestricted Funds (£)	Restricted Funds (£)	Total (£)
Restricted funds	0.00	10,000.00	10,000.00
Designated reserves*	5,000.00	0.00	5,000.00
Unrestricted free reserves	9,751.36	0.00	9,751.36
Total funds / reserves	14,751.36	10,000.00	24,751.36

*Designated Reserves are set aside for future Conference