



Trustees' Annual Report Letter

Kleefstra Syndrome UK

Charity Number: 1208059

Reporting Period: 30th April 2024 – 31st December 2024 (1st year accounts)

Trustees' Annual Report for the Year Ended 31.12.2024

Charity Name: Kleefstra Syndrome UK

Charity Registration Number:1208059

Reporting Period: 30th April 2024 – 31st December 2024

Trustees

Wendy Hocking – Chair	Appointed 30th April 2024
Vytautas Berzanskis – Treasurer	Appointed 30th April 2024
Anna Gibbs – Secretary	Appointed 30th April 2024
Barbara Roberts	Appointed 30th April 2024
Dr Katherine Palmer	Appointed 30th April 2024
Catherine Darlaston	Appointed 30th April 2024 - Resigned 11th December 2024.
Hannah Banfield	Appointed 1st May 2024
Courtney Halliwell	Appointed 1st May 2024

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 first 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 2024 national family conference held in July 2024.
 - 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 £25,000, derived from individual donations and small fundraising activities. Expenditure was in line with our charitable objectives, including support activities, event planning, and communications. We have set aside as designated reserves the sum of £5,000 for the upcoming conference.

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.



**KLEEFSTRA
SYNDROME
UK**

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

FOR THE YEAR ENDING 31st December 2024 (period from 30th April 2024 - 31st December 2024)

Balance at Nat West Account 30.04.2024	20535.35
Balance at Paypal 30.04.2024	<u>575.00</u>
Available reserves as at 30.04.24	21,108.35

INCOME

Payments for Conference attendance	1,675.46	
Plus Subscriptions/Donations/fundraising	1,673.76	
<u>Sale of Kelsey Bears and Merchandise</u>	<u>237.37</u>	
	3,586.59	24,694.94

Less Expenditure

Fees (PP)	16.5
Zoom (NW)	155.88
Markel Insurance (NW)	134.40
SumUP Payment charges	3.71
NSPCC (NW)	60.00
Website Maintenance	138.24
Merchandise (Bears, pens etc.)	1,449.00
<u>DBS Checks</u>	<u>100.00</u>
	2,057.73

Less Conference Expenditure

Trustees Reimbursement Accommodation (NW)	238
Trustees Reimbursement travel (NW)	308.54

Wychwood park (Conference) (NW)	4,829.95
Delegates Expenses	
(Accommodation,Travel etc.)(NW)	375.70
Wingate Special (NW)	1,800.00
Merchandise for Conference (NW)	825.03
Apparel (NW)	429.01
Dave Benson Phillips (NW)	787.00
Photography/Video	<u>1,620.00</u>
	11,213.23

Total expenditure paid out.	13,270.96
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11,423.98

Balance sheet.

Monies held at Nat West 31.12.2024	10434.68
Monies held at Paypal 31.12.2024	989.30
Total monies (cash held 31.12.2024)	11,423.98

Total monies available (Reserves) at year end 31.12.2024	11,423.98
Designated Reserves*	5,000.00
Free Reserves	6,423.98

*Designated Reserves are set aside for the future conference