

## **Sparkles: Supporting Children with Down's Syndrome**

**[N.B. This report was originally submitted on time in January 2024, but it was noticed in March that there was an error in the figures inputted in the Annual Return – which showed the amount for YE March 22 rather than YE March 23 (although the figures in this document and the submitted accounts were correct). Therefore the whole submission had to be withdrawn and resubmitted on 25<sup>th</sup> March 2024, hence the return showing as late]**

**Charity number: 1168036**

The trustees are pleased to present their annual report together with the financial statements of the charity for the period ending March 2023.

### **Chair's Report**

This year Sparkles has supported over 50 children with Down's syndrome in and around Buckinghamshire. Of these fifty, 18 children are accessing weekly specialist speech and language therapy, 17 are accessing termly physiotherapy and 11 are accessing termly occupational therapy. We are also continuing with our EHCP support package, which this year has helped seven children. The year ending March 2023 has seen the numbers of children we support start to increase from the artificially low numbers accessing Sparkles during and immediately following the Covid period. On the one hand, it has been fantastic for us to be able to increase our impact again and reach out to many new families, this has also increased the financial pressures on Sparkles, at a time when we have also been experiencing increased costs for our services and lower levels of donations and fundraising than we have historically achieved.

This has meant that in the following year, whilst we have been excited to trial additional activities to expand the age range of children we support, through Makaton classes for babies and funding places for former Sparklers to attend Bright Bloom Speech and Language summer camp, it is uncertain whether we will be able to add these to our regular 'portfolio' of activities. Although we retain the ambition to add to our regular activities, we need to prioritise first and foremost our core therapy offer to pre school children (speech and language, occupational therapy and physiotherapy) until our funds are more stable again.

### **Big Step Forward**

This year the Big Step Forward took place in May 2022 at Ashridge Woods. Many families took part and enthusiastically raised sponsorship money for us, making our grand total **£3,287**. Thank you again to everyone who organised, joined us or sponsored us from afar!

### **Christmas FUNdraiser and party**

In December 2022 we held our now traditional Christmas Party and raffle, again involving interactive story-telling and parachute games from Story Box, and some Christmassy stalls to purchase cards and cakes, together with a toy tombola. Altogether this raised **£1,180**.

### **World Down's Syndrome Day auction**

In March 2023 Sparkles held another online auction for World Down's Syndrome Day, with prizes including an overnight stay at Foxes Hotel in Minehead, a tricycle, craft beer, hand-knitted dolls and a range of vouchers from local companies. **Altogether the auction raised £1,255.91.**

### **Other donations**

We were lucky enough to be picked for the Tesco Community Grant, which raised us £1,480.

A huge thank you to our other donors this year, who have included Liberis Charity (£1,500), the Steeple Claydon branch of the Coop, which raised £1,199 for us in February, 2023, Mencap Amersham and Chesham branch (£1,000), Action 4 Youth (£590) and £4,171 from PCR Biosystem. We have also had £200 raised by a local Brownie Pack and £131.40 from AEPT Physical Training, and many local schools and nurseries donating to us for World Downs Syndrome Day in March.

### **WhatsApp groups**

During and following the Covid 19 pandemic it also has become clear to us how valuable to Sparkles Parents WhatsApp has been to all our members, old and new alike. The group currently has 59 members and has been a hugely useful resource for all to connect with each other, share parenting experiences, worries, concerns, questions around therapies, health, the DLA and EHCP process, as well as "proud parent moments". There is also a 'spin off' WhatsApp group for Sparklers at School, with 35 members.

### **Summary of the Sparkles Education and Health Care Plan (EHCP) package of support**

Since 2020, Sparkles has been offering parents support for applying for EHCPs in preparation for their children starting school.

#### **Aims of the programme**

- To ensure that financial barriers are not an obstacle to Sparkles children receiving the high quality EHCPs they need and deserve for a successful transition to school.
- To support Sparkles families navigate the EHCP process, by providing SLT, occupational therapy and physiotherapy reports, expertise and a representative to liaise with their local authority in the process.

- To reduce the need for families to go down the tribunal route, by providing extra evidence on the level support the child requires, and/or how this support is phrased in the document to ensure it is specific and legally binding, once the EHCP has reached draft stage, if the initial draft is deemed inadequate.
- To provide reports and evidence which can be used in tribunals, if required, thereby reducing the cost to families who have to go to tribunal and fund their own private assessments and consultancy fees.

### **EHCP support Outcomes**

As a result of EHCP support input, the families have been able to obtain much better EHCPs for their children:

- Achieving clarity and accountability of the hours of support stated in the EHCP. Final plans stated how many contact/direct hours of therapy were to be provided, and then, in addition, how many hours for report writing, attending annual reviews and liaising with staff and parents. These were all greater than the initial hours stipulated in the draft plans.
- The plans secured have very clear wording around the level of specialism required. For example, “therapist must be specialist in Down’s syndrome”.

In 2022/2023, the Sparkles EHCP support ensured 1-2-1 support for a child’s nursery placement was secured (after a considerable delay to them being granted High Needs Block Funding), another child was able to secure their preferred school placement, and other families were supported to take their initial EHCP to appeal.

### **Achievements and Performance**

This year’s achievements include:

- The continued provision of speech and language therapy, physiotherapy and Occupational therapy. This year has seen more new referrals, both from professionals (health visitors etc), and self-referrals from our Facebook page and via word of mouth from existing families.
- The continued support for children in their transition to primary school. Children are provided with intensive block of speech therapy over the summer holidays prior to starting school. The therapist liaises with schools to create a bespoke package of therapy in order to ease the transition. This includes familiarisation with vocabulary relevant to the school environment, teachers and the first topic to be covered at school. This is followed up by two visits into school during the first year. Teachers and teaching assistants have reported this to

be a valuable resource that helps them to support the child better and have a greater understanding of their needs and abilities.

- Physiotherapy and Occupational therapy sessions also continue to be provided in the first year of school in order to ease the transition and help children settle into their new environment.
- Continuing to support families through the EHCP process, by providing expertise, reports to evidence the children's therapy needs and a representative to liaise with the local authority in the process.

## **Financial Review**

### **Review of the charity's financial position at the end of the period**

Cash reserves are needed to bridge the gap between the spending and receiving of resources and to ensure continuity of the provision of core therapies. The trustees consider that the ideal level of reserves as at 31st March 2023 would be at least £40,000 to cover the provision of one year's speech and language, physio and occupational therapy to all current members, along with the current level of EHCP support we provide.

The actual level of cash reserves held at 31 March 2023 were £85,311, lower than our position on 31 March 2022 of £91,150.

An increase in EHCP support and occupational therapy has resulted in a net cash outflow of (£5,838).

The Sparkles Lottery continues to benefit Sparkles, and we are hopeful will continue to grow in numbers, and have plans in place to establish more external sources of income.

Based on the existing reserves and cash resources, together with fundraising plans for the future, we are confident that Sparkles remains a going concern and can satisfy its liabilities as they fall due.

In closing, we would like to thank our team of therapists for their continued hard work, support and championing of our children, our generous donors, the trustees and committee members, all our families and not least our amazing children, who are at the heart of what we do.

Meryn Brown (Chair) and Dylan Jones (Treasurer), 29<sup>th</sup> January 2024

To find out more about Sparkles please visit our website: [www.sparkles.org.uk](http://www.sparkles.org.uk), see our Facebook page: <https://www.facebook.com/SparklesCharity> or email us at [SparklesCharity@gmail.com](mailto:SparklesCharity@gmail.com) or [Sparklestrusteechair@gmail.com](mailto:Sparklestrusteechair@gmail.com)

## **Objectives and Activities**

The purposes of the charity are:

Sparkles is a small, parent-led charity that funds the provision of speech and language, physiotherapy and occupational therapy sessions to pre-school children with Down's syndrome living in and around Buckinghamshire. We also organise appropriate leisure and recreational activities for our members and their children, which provides a valuable support network to parents and siblings.

Today, the therapeutic support that we offer through Sparkles is a valuable addition to NHS services, which are not compromised by joining.

Our vision is that all children with Down syndrome in Buckinghamshire; from birth to infant school age; have the opportunity to reach their full potential through early speech and language therapy, physiotherapy and occupational therapy.

## **Activities**

Shaping our activities is our mission to provide children with Down syndrome with responsive, high quality therapeutic support that enriches their lives and supports their families. This is delivered in four main areas: Speech and language therapy, physiotherapy, occupational therapy and support for families.

## **Speech and Language Therapy**

Sparkles speech and language therapy sessions take place at Children's Centres in High Wycombe and Aylesbury. Each session is 45 minutes long, weekly (term time only) and held in groups of no more than 3 children and their parent / carer.

Children with Down's syndrome will usually experience challenges with communication to varying degrees, including receptive (understanding) language and expressive (speaking and composing sentences) language skills.

Carried out by specialist speech and language therapists, the sessions are based on Makaton: a system designed to support spoken language where signs and symbols are used alongside speech, in spoken word order.

Our speech and language therapy focuses on helping our children to talk, but also covers the essential skills needed to communicate effectively. The sessions are designed to engage our members from a young age and include:

- Music, songs and games;
- Listening and comprehension;

- Turn taking;
- Picture and word matching;
- Lip seal and tongue control exercises;
- Phonics; and
- Combining words and sequencing sentences

The sessions are provided at no cost to the families. Parent's report that there is either a lack of speech and language therapy available on the NHS or an inconsistent level of provision and that Sparkles is a lifeline, easing frustration by enabling communication and helping parents to feel supported.

### **Physiotherapy**

At Sparkles, we offer 3 to 6 physiotherapy sessions each year with a specialist practitioner, depending on the age and need of the child. The sessions are 45 minutes long, one-to-one with the child and parent/carer, and based in a children's physiotherapy clinic in High Wycombe.

Children with Down's syndrome can have low muscle tone and hyper-flexibility, which can make mastering gross motor skills harder. Delays in physical development are not uncommon. Targeted physiotherapy helps our children achieve major milestones such as sitting, crawling and walking. The sessions are individually tailored, fun and child-centred enabling children to reach their full potential and grow with confidence. Parents are provided with a programme of exercises and activities to follow at home to support their child.

The sessions are provided at no cost to the families, except where late cancellation fees may apply.

### **Occupational Therapy**

At Sparkles, we offer 3 to 6 occupational therapy sessions each year, depending on the age and need of the child. The sessions are 45 minutes long, one-to-one with the child and parent/carer, and based at PACE, a highly equipped clinic in Aylesbury. PACE provides the funding for under 2s, whilst Sparkles takes on the costs for the 2, 3 and 4 year olds.

### **Public Benefit**

In planning our activities for the year and our objectives for the future, the trustees have considered the Charity Commission's guidance on public benefit, including the guidance on public benefit and fee charging. Sparkles relies on fundraising by its members, grants and donations in order to cover the cost of the therapies provided. In accordance with the purposes of the charity, all therapies are provided at no cost to the families attending. This is due to consideration of accessibility for those on

low incomes.

## **Objectives**

- 1 To identify the number of families of children with Down's syndrome, in our target area, not currently receiving our services and make them aware of Sparkles by working closely with other organisations and professionals.
2. To evaluate our therapeutic services to ensure we are providing appropriate, high quality services, that make the best use of our resources.
3. To establish external funding streams to create a financially sustainable service with funding from external sources composing 50% of our income by the end of 2020.
4. To improve internal communications with parents and families to engage more parents to be more actively involved in Sparkles and enable annual succession planning as children leave Sparkles.
5. To improve our marketing and communication to support our objectives, with a new website, and new marketing materials targeted at parents and at professionals.

## **Structure, Governance and Management**

### Governing Document

Sparkles governing document is an association model constitution and the charity is a Charitable Incorporated Organisation (CIO) with voting members other than its charity trustees.

### Appointment of charity trustees

- (1) At every annual general meeting of the members of the CIO, 1/3rd of the charity trustees shall retire from office. If the number of charity trustees is not 3 or a multiple of 3, then the number nearest to 1/3rd shall retire from office, but if there is only 1 charity trustee, he or she shall retire;
- (2) The charity trustees to retire by rotation shall be those who have been longest in office since their last appointment or reappointment. If any trustees were last appointed or reappointed on the same day those to retire shall (unless they otherwise agree among themselves) be determined by lot;
- (3) The vacancies so arising may be filled by the decision of the members at the annual general meeting; any vacancies not filled at the annual general meeting may be filled as provided in sub clause (5) of this clause;
- (4) The members or the charity trustees may at any time decide to appoint a new charity trustee, whether in place of a charity trustee who has retired or been removed in accordance with clause [15] (Retirement and removal of charity trustees), or as an additional charity trustee, provided that

the limit specified in clause [12(3)] on the number of charity trustees would not as a result be exceeded;

(5) A person so appointed by the members of the CIO shall retire in accordance with the provisions of sub-clauses (2) and (3) of this clause. A person so appointed by the charity trustees shall retire at the conclusion of the next annual general meeting after the date of his or her appointment, and shall not be counted for the purpose of determining which of the charity trustees is to retire by rotation at that meeting.





CHARITY COMMISSION  
FOR ENGLAND AND WALES

Charity Name  
**SPARKLES- Supporting Children with Down's Syndrome**

168036

## Receipts and payments accounts

CC16a

For the period  
from

Period start date  
01/04/2022

To

Period end date  
31/03/2023

### 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 £
<b>A1 Receipts</b>					
Donations	30,225	-	-	30,225	17,141
Fund Raising- The Ball		-	-	-	
Fund raising- Lottery	3,430	-	-	3,430	
Fund raising- GYBO		-	-	-	
Fund raising- Other	2,635	-	-	2,635	
Interest	178	-	-	178	94
		-	-	-	-
		-	-	-	-
<b>Sub total (Gross income for AR)</b>	<b>36,468</b>	<b>-</b>	<b>-</b>	<b>36,468</b>	<b>17,234</b>
<b>A2 Asset and investment sales, (see table).</b>					
	-	-	-	-	
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total receipts</b>	<b>36,468</b>	<b>-</b>	<b>-</b>	<b>36,468</b>	<b>17,234</b>
<b>A3 Payments</b>					
Speech & Language Therapy	13,647	-	-	13,647	15,182
Physiotherapy	8,620	-	-	8,620	10,115
Leap OT	1,980	-	-	1,980	1,180
Expenses- The Ball	-	-	-	-	
Expenses- Lottery Prizes	1,656	-	-	1,656	1,534
Expenses- Emma Hopkins	13,517	-	-	13,517	12,485
Expenses- Other	2,787	-	-	2,787	875
		-	-	-	
		-	-	-	
<b>Sub total</b>	<b>42,207</b>	<b>-</b>	<b>-</b>	<b>42,207</b>	<b>41,369</b>
<b>A4 Asset and investment purchases. (see table)</b>					
	-	-	-	-	
	-	-	-	-	
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total payments</b>	<b>42,207</b>	<b>-</b>	<b>-</b>	<b>42,207</b>	<b>41,369</b>
<b>Net of receipts/(payments)</b>	<b>- 5,739</b>	<b>-</b>	<b>-</b>	<b>- 5,739</b>	<b>- 24,135</b>
<b>A5 Transfers between funds</b>					
	-	-	-	-	-
<b>A6 Cash funds last year end</b>	<b>91,150</b>	<b>-</b>	<b>-</b>	<b>91,150</b>	<b>115,285</b>
<b>Cash funds this year end</b>	<b>85,411</b>	<b>-</b>	<b>-</b>	<b>85,411</b>	<b>91,150</b>



## 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 £
<b>B1 Cash funds</b>		52,143	-	-
		31,422	-	-
		1,846	-	-
	<b>Total cash funds</b>	<b>85,411</b>	<b>-</b>	<b>-</b>
(agree balances with receipts and payments account(s))				


	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
<b>B2 Other monetary assets</b>		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
<b>B3 Investment assets</b>			-	-
			-	-
			-	-
			-	-
			-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
<b>B4 Assets retained for the charity's own use</b>			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
<b>B5 Liabilities</b>			-	
			-	
			-	
			-	
			-	

Signed by one or two trustees on behalf of all the trustees

Signature	Print Name	Date of approval
	DYLAN JONES	07/01/24



Section A

Independent Examiner's Report

Report to the trustees/ members of	Charity Name SPARKLES- SUPPORTING CHILDREN WITH DOWN SYNDROME		
On accounts for the year ended	31 <sup>ST</sup> MARCH 2023	Charity no (if any)	1168036
Set out on pages	(remember to include the page numbers of additional sheets)		

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31 / 03 / 2023.

**Responsibilities and basis of report** As the charity trustees of the Trust, 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 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 (other than that disclosed below \*) in connection with the examination which gives me cause to believe that in, any material respect:

- accounting records were not kept in accordance with section 130 of the Act or
- the accounts do not accord with the accounting records

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn 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: Raj Kumar Gupta Date: 07/01/24

Name: RAJ GUPTA

Relevant professional qualification(s) or body (if any): CIMA / CIPFA

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