

THE FAMILIES AND FRIENDS OF THE EPILEPSY SOCIETY

England & Wales · Charity number 1200293

Details

Status Registered

Legal form CIO

Registered 2022-09-06

Register [View on the Charity Commission register](#)

Contact

Address 14 Slicketts Lane
Edlesborough
Dunstable
LU6 2JD

Phone 07890555391

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Activities

Objects: TO RELIEVE THE NEEDS OF PEOPLE WHO HAVE EPILEPSY AND SOME DEGREE OF LEARNING DISABILITY AND ARE RECEIVING SPECIALIST RESIDENTIAL CARE AT THE EPILEPSY SOCIETY, BY PROVIDING GRANT FUNDING FOR ACTIVITIES AND FACILITIES DIRECTED TO IMPROVING THEIR QUALITY OF LIFE AND FITNESS AND TO IMPROVE THE MENTAL HEALTH AND WELL-BEING OF CARE STAFF.

Activities: To relieve the needs of people who have epilepsy and some degree of learning disability and are receiving specialist residential care at the Epilepsy Society, by providing grant funding for activities and facilities directed to improving their quality of life and fitness and to improve the mental health and well-being of care staff

Classification

- **How:** Makes Grants To Organisations, Provides Buildings/facilities/open Space
- **What:** Disability
- **Who:** People With Disabilities

Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-12-31	£22,520	£15,815	-	-
2024-12-31	£25,457	£10,448	-	-
2023-12-31	£23,572	£20,050	-	-

Trustees

Name	Role	Appointed
NICOLA DAVIES	Chair	2022-08-26
Andrew Camp		2025-03-02
David Josephs		2022-08-26
Jane Margaret Knight		2025-03-02
Jennifer Mary Back		2025-03-02
John Davies		2022-08-26
Julie Josephs		2022-08-26
Penelope Theresa Munday		2022-08-26
Philip John Munday		2022-08-26
Zahra Jalili		2022-08-26

THE FAMILIES AND FRIENDS OF THE EPILEPSY SOCIETY

England & Wales - Charity number 1200293

Accounts



Chair's Report for FFES AGM Friday May 1st, 2026

This has been the third full year of operation for our charity, FFES, which exists to improve the quality of life of people cared for by the Epilepsy Society, and those who support them. FFES now has a Membership of 63 and an Honorary Membership of 38.

There are still many residents who live at the Epilepsy Society who no longer have living relatives so our philosophy as a charity has always been to ensure everyone who lives at the ES is included in all that we do.

FFES has an excellent Board of Trustees, and we meet monthly with a packed agenda, ensuring we discuss the issues which most concern us and our members at the time. Trustees have worked tirelessly in a variety of volunteering roles to ensure we have strong governance, always focussing on ways in which we can improve and enhance quality of life for the people who live at ES as well as their support staff. We are extremely sorry to report that one of our Trustees, Lorna Soesman sadly died at the beginning of the year and will be greatly missed.

We are always really grateful to our members, many of whom volunteer their time to help maintain the Nature Trail and the Memory Garden as well as gardens in the Houses where their loved ones live; support our Sunday Sounds 'events through the provision of delicious food, or by assisting at the events themselves; support and attend events we run on the Nature Trail; and, so important for us as a small charity, the many, many people who have donated money to support one or more of our initiatives. We thank them all for their kindness and generosity.

Thanks to the initiatives of our Trustees and Members, we believe that we have helped to enhance the lives of the people who live at Epilepsy Society in a variety of ways. Everyone, (staff, residents as well as relatives), has been able to look forward to the monthly Sunday Sounds events in the Recreation Hall with a different variety of Musical Bands on stage each month. All look forward with eagerness to the delicious homemade refreshments provided free for everyone attending. Last Autumn saw the welcome addition of the Saturday Pump Room café in the Rec Hall where people who live on site enjoyed a variety of games, a nail bar and also, this Spring, a disco with our own resident DJ!

Many people enjoy their regular trips to the Nature Trail and have participated in events, such as the animal petting farm which we held last year and which we have already held at the end of March this year. The Paella van (with accompanying music) was a huge success last summer, as were the picnics and games on the trail. The Autumn pumpkin competition was fun too even though rain stopped play outside and all the pumpkins had to be weighed

in from a wheelbarrow in the Rec Hall! Maintaining and continuing to grow and develop the Nature Trail has been a joy to all the volunteers working there. Spring on the Trail arrived with plenty of colour this year in the form of all the daffodils, tulips and hyacinths which we had planted in the Autumn. A lovely site to see!

There are regular attendees to the two swimming sessions held each week at Woodrow High House and Leisure Centre, with very grateful thanks to our Trustee, Julie, who set up the Tuesday sessions.

These are both very enjoyable sessions, attended also by the Physiotherapist.

Members have had opportunities to meet with the ES Trustees in 2 virtual meetings last year as well as attending meetings with our Director of Care and Director of Business Development and also with a Care Manager from Rennie Grove Peace Hospice Care.

We have now established a practice that at Christmas all Support Staff receive a voucher from FFES to use in the café. This has been a small recognition of all the work support staff do for our loved ones

Our FFES website (<https://www.ffes.info>) has helped take the charity to a different level, and provides updated information for members and non-members as well as providing a platform for epilepsy related articles etc. As lobbying becomes increasingly important to us, we have a social platform available if needed.

Also established is a good network of mutual support set up through WhatsApp groups amongst our members and regular emails, ensuring everyone is kept in the loop about anything Epilepsy Society related. The Newsletters established during the year by one of our Trustees are also an excellent form of communication in Houses, with staff and with relatives.

You will see from our Treasurer's report that our finances are currently healthy thanks to the membership subscriptions and the donations we receive and this enables us to plan well for the coming year in terms for example of hiring bands for Sunday Sounds, financing the Ark Farm on the Nature Trail, replenishing summer plants and developing our sculpture and seating areas on the trail as well as buying summer plants for the Phoenix Garden, providing refreshments for our events etc etc.as well as having money in reserve so we can plan further into the future. Your membership subscriptions and donations are really important to us so thank you so much for your generosity.

There have been many challenges over the past year and the one that has troubled members the most, has been the low level of Medical Support and Cover at the Epilepsy Society. At the end of last year, we were very pleased to hear that Gemma Lee (previously working as a nurse in QEH) had been appointed as a full time Lead Nurse across the site. Members remain concerned however about the few Consultancy hours from Neurology available at Chalfont and the fact that we still do not have an Epilepsy Specialist Nurse on site.

Another focus last year was to see the level of Activities both in house and externally improve across the site as this remains inconsistent from Service to Service. FFES Trustees have been pushing for an Activities Coordinator to be appointed, and we are hoping that this position may come to fruition later in 2026. We also pressed for Annual Reviews to be re-established across the site as a means of focussing on a person-centred approach to activity planning. Our aim remains to gain greater consistency across the site for the Keyworker role. We believe that a job description and better training would improve this role significantly.

Amongst our challenges remains the ongoing challenge of improving dialogue and discussion directly with the Epilepsy Society Trustee Board. Currently we have 2 virtual meetings a year with them but no direct face to face contact which we feel is essential if we are to help Epilepsy Society Trustees towards a better understanding of Care Services and the needs of our loved ones. We remain firm in our belief that relatives across the site can play an important role in advocating for the people who live at Chalfont and for that reason representation either at Board level or in coproduction groups with Senior Management can make this belief a reality.

We all now hope that a decision on the Epilepsy Society Planning application will be with us very soon (on or by June 1st appears to be the latest estimate). It has been a long wait with the decision being in the hands of the Secretary of State.

Despite everything, this year has been a year of considerable progress for the Charity and everyone in FFES should feel a sense of delight in seeing some of the differences we are all making to bring more joy to the lives of our loved ones. Whether it be thorough volunteering, attending events, making donations or paying membership fees to FFES, all of you are making your own difference in a way that we can all be proud of.

Thank you.
Nicola Davies.
FFES Chair.



CHARITY COMMISSION
FOR ENGLAND AND WALES

Families and Friends of the Epilepsy Society

1200293

Receipts and payments accounts

CC16a

For the period from	Period start date 01/01/2025	To	Period end date 31/12/2025
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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 £
A1 Receipts					
Subscriptions with NatureTrail Donations	3,500	-	-	3,500	2,185
Other Donations (Including Nature Trail)	-	5,264	-	5,264	2,706
Café Voucher Scheme Donations	-	-	-	-	1,357
RL Charity Admin Donation	-	-	-	-	500
Sunday Sounds Donations.	-	9,244	-	9,244	1,333
DJ Chalfont Restored Donations.	-	2,900	-	2,900	6,075
DJ Bursary	-	-	-	-	10,000
HMRC Gift Aid	1,612	-	-	1,612	1,301
Sub total (Gross income for AR)	5,112	17,408	-	22,520	25,457
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	5,112	17,408	-	22,520	25,457
A3 Payments					
Bank Charges	38	-	-	38	68
Treasurer Expenses	24	-	-	24	27
Zoom Subscription	156	-	-	156	156
Nature Trail	-	3,165	-	3,165	4,230
Café Voucher Scheme to ES	-	1,608	-	1,608	1,296
Sunday Sounds	-	8,589	-	8,589	4,278
Just Giving Subscription	-	216	-	216	90
RL Charity Admin	-	-	-	-	343
Other Payments	-	2,019	-	2,019	-
Sub total	218	15,597	-	15,815	10,488
A4 Asset and investment purchases. (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	218	15,597	-	15,815	10,488
Net of receipts/(payments)	4,894	1,811	-	6,705	14,969
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	13,823	24,909	-	38,732	23,763
Cash funds this year end	18,717	26,720	-	45,437	38,732

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	HSBC Charitable Bank Account	18,717	26,720	-
		-	-	-
		-	-	-
	Total cash funds	18,717	26,720	-
(agree balances with receipts and payments account(s))		OK	OK	OK


Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-

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

Categories	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	
			-	
			-	
			-	

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

Signature	Print Name	Date of approval
	John T Davies	17.01.26

Audited by **Ron Makinen** 

17.01.26

THE FAMILIES AND FRIENDS OF THE EPILEPSY SOCIETY

England & Wales - Charity number 1200293

Accounts



Chair's Report for FFES 2024

14.02.25

This has been the second full year of operation for our charity, FFES, which exists to improve the quality of life of people cared for by the Epilepsy Society, and those who support them. FFES now has a membership of 57 members and an Honorary Membership list of 27. There are still many residents who live at the Epilepsy Society who no longer have living relatives so our philosophy as a charity has always been to ensure everyone who lives at the ES is included in all that we do.

We have an excellent Board of Trustees who have worked tirelessly in a variety of volunteering roles to ensure we have strong governance, always focussing on ways in which we can improve and enhance quality of life for the people who live at ES as well as their support staff.

We are always really grateful to our members, many of whom volunteer their time to help maintain the Nature Trail and the Memory Garden as well as gardens in the Houses where their loved ones live; support our Sunday Sounds 'events through the provision of delicious food, or by assisting at the events themselves; support and attend events we run on the Nature Trail; and, so important for us as a small charity, the many, many people who have donated money to support one or more of our initiatives. We thank them all for their kindness and generosity.

Thanks to the initiatives of our Trustees and Members, we believe that we have helped to enhance the lives of the people who live at Epilepsy Society in a variety of ways. Everyone, (staff, residents as well as relatives), has been able to look forward to the monthly Sunday events in the Recreation Hall with a different variety of Musical Bands on stage each month. All look forward with eagerness to the delicious homemade refreshments provided free for everyone attending.

Many people enjoy their regular trips to the Nature Trail and have participated in events, such as the small animal petting farm and the picnics and games during the summer months. Maintaining and continuing to grow and develop the Nature Trail has been a joy to all the volunteers working there. We await with anticipation the arrival of Spring on the Trail and gradually see the colour return to it.

There are regular attendees to the two swimming sessions held each week at Woodrow High House and Leisure Centre, with very grateful thanks to our Trustee, Julie. These are both very enjoyable sessions, attended also by the Physiotherapist.

Members have had opportunities to meet with the ES Trustees in 2 virtual meetings last year as well as attending meetings with our Medical Director, our Director of Care and Director of Business Development and also with the Learning Disability Nurse at Wexham Park Hospital.

Another great step forward for us as a charity is the formation of our own website (<https://www.ffes.info>) and that has been possible through the extremely generous free time given by a friend of one of our Trustees. The website has helped take the charity to a different level, and provides updated information for members and non-members as well as providing a platform for epilepsy related articles etc. As lobbying becomes increasingly important to us, we have a social platform available if needed.

Also established is a good network of mutual support set up through WhatsApp groups amongst our members and regular emails, ensuring everyone is kept in the loop about anything Epilepsy Society related. The Newsletters established during the year by one of our Trustees are also an excellent form of communication in Houses, with staff and with relatives.

You will see from our Treasurer's report that our finances are currently healthy thanks to the membership subscriptions and the donations we receive and this enables us to plan well for the coming year in terms for example of hiring bands for Sunday Sounds, financing the Ark Farm Petting again this year on the Nature Trail , replenishing summer plants and developing our sculpture and seating areas on the trail as well as buying summer plants for the Phoenix Garden, providing refreshments for our events etc etc.as well as having money in reserve so we can plan further into the future. Your membership subscriptions and donations are really important to us so thank you so much for your generosity.

Many challenges await us in the coming year and work has already started! Our main focus, and the one that is troubling members the most, is the low level of Medical Support and Cover at the Epilepsy Society. This must be our main focus at FFES this year to lobby for improvements in Medical Services, both in terms of Consultancy hours available and through employment of an Epilepsy Specialist Nurse.

Another focus is to see the level of Activities both in house and externally improve across the site as this remains inconsistent from Service to Service. FFES Trustees have already begun meeting with Rebecca to see how we as relatives can work more closely with ES on this target, initially aiming for everyone who wants an Annual Review to have one as a means of focussing on a person-centred approach to activity planning. Our aim is also to gain greater consistency across the site for the Keyworker role. We believe that a job description and better training would improve this role significantly.

Amongst our challenges remains the ongoing challenge of improving dialogue and discussion directly with the Epilepsy Society Trustee Board. Currently we have 2 virtual meetings a year with them but no direct face to face contact which we feel is essential if we are to help Epilepsy Society Trustees towards a better understanding of Care Services and the needs of our loved ones.

Despite everything, this year has been a year of considerable progress for the Charity and everyone in FFES should feel a sense of delight in seeing some of the differences we are all making to bring more joy to the lives of our loved ones. Whether it be thorough volunteering, attending events, making donations or paying membership fees to FFES, all of you are making your own small difference in a way that we can all be proud of.

Thank you.

Nicola Davies
FFES Chair.

FFES
14 Slicketts Lane
Edlesborough
Nr Dunstable
Beds.
LU6 2JD

27 Plantation Road
Leighton Buzzard
Beds
LU7 3HJ

28th Jan 2025

Dear FFES Trustees,

Independent Examiner's Report to the Trustees of FFES
(FFES being the Families and Friends of the Epilepsy Society)

I report to the trustees on my examination of the accounts of the FFES for the year ended 31 December 2024.

Responsibilities and basis of the report

As the charity trustees of the FFES 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 FFES 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 giving me cause to believe that in any material respect :

1. accounting records were not kept in respect of the FFES as required by section 130 of the Act; or
2. the accounts do not accord with those records.

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.

Signed : *R Make*

Name : *RONALD MAKINEN*

Retired Cost Engineer

Address :
27 Plantation Road, Leighton Buzzard, Beds LU7 3HJ.

Date : *28/1/25*

FFES
14 Slicketts Lane
Edlesborough
Nr Dunstable
Beds.
LU6 2JD

27 Plantation Road
Leighton Buzzard
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28th Jan 2025

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Independent Examiner's Statement

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1. accounting records were not kept in respect of the FFES as required by section 130 of the Act; or
2. the accounts do not accord with those records.

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.

Signed : *R Make*

Name : *RONALD MAKINEN*

Retired Cost Engineer

Address :
27 Plantation Road, Leighton Buzzard, Beds LU7 3HJ.

Date : *28/1/25*

THE FAMILIES AND FRIENDS OF THE EPILEPSY SOCIETY

England & Wales - Charity number 1200293

Accounts



Trustees Report 2023

The Families and Friends of the Epilepsy Society

This has been the first full year of operation for our charity, which exists to improve the quality of life of people cared for by the Epilepsy Society, and those who support them.

It has been a year of considerable progress. We were able to fund and oversee the development of a new Nature Trail within the grounds of the Epilepsy Society, which has proven hugely popular with both residents and staff alike. It provides a place of fascination and tranquility.

We have also initiated a programme of weekend activities for residents under the brand Sunday Sounds. We've been able to hire a number of bands who have entertained residents, their families and their support workers.

We've run a series of information sessions for our members.

We could not have achieved any of this without a number of people. The Trustees would like to thank the following:

The many people who have volunteered their time to help build and maintain the Nature Trail.

The many people who have supported our events through the provision of delicious food, or by assisting at the events themselves.

The many, many people who have donated money to support one or more of our initiatives. We thank them all for their kindness and generosity.

We work closely with the staff at the Epilepsy Society, and would like to thank them all for their support and kindness.

We are grateful to the senior management team and trustees of the Epilepsy Society for granting permission for us to develop the Nature Trail on the grounds of the Epilepsy Society.



Receipts and payments accounts

For the period from	Period start date 01/01/2023	To	Period end date 31/12/2023
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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 £
A1 Receipts					
Subscriptions and Donations	2,020	-	-	2,020	1,630
National Lottery Grant for Nature Trail	-	-	-	-	9,995
Nature Trail Grants and Donations	-	5,043	-	5,043	1,640
Café Garden Grant	-	-	-	-	150
Café Voucher Scheme Donation	-	-	-	-	1,000
Russell House Plants Donation	-	-	-	-	200
Charity Admin Donation	-	-	-	-	500
Sunday Sounds	-	12,155	-	12,155	-
Hydro	-	2,400	-	2,400	-
DJ Comms	-	1,000	-	1,000	-
Winter Wonderland	-	873	-	873	-
HMRC Gift Aid	81	-	-	81	-
Sub total (Gross income for AR)	2,101	21,471	-	23,572	15,115
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	2,101	21,471	-	23,572	15,115
A3 Payments					
Bank Charges	68	-	-	68	67
Treasurer Expenses	44	-	-	44	67
Zoom Subscription	144	-	-	144	144
Grants Online Subscription	180	-	-	180	36
Café Garden	-	-	-	-	27
Memory Garden	-	-	-	-	5
Nature Trail	-	-	-	-	9
Nature Trail Grants and Donations	-	16,440	-	16,440	1,328
Café Voucher Scheme Donation	-	-	-	-	1,000
Café Garden Grant	-	-	-	-	150
Russell House Plants Donation	-	-	-	-	200
Sunday Sounds	-	1,749	-	1,749	-
Nature Trail Paths to ES	511	-	-	511	-
Illumination Event to ES	-	250	-	250	-
Winter Wonderland to ES	-	500	-	500	-
Winter Wonderland Stall	-	164	-	164	-
Sub total	947	19,103	-	20,050	3,033
A4 Asset and investment purchases. (see table)					
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	947	19,103	-	20,050	3,033
Net of receipts/(payments)	1,154	2,368	-	3,522	12,082
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	9,434	10,807	-	20,241	8,159
Cash funds this year end	10,588	13,175	-	23,763	20,241

R. Mahony
25/1/24

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	HSBC Charitable Bank Account	10,588	13,175	-
		-	-	-
		-	-	-
	Total cash funds	10,588	13,175	-
(agree balances with receipts and payments account(s))		OK	OK	OK

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-

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

Categories	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	
			-	
			-	

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

Signature	Print Name	Date of approval
<i>John T Davies</i>	John T Davies	? 25/1/24