

Annual Review 2004



*Breaking isolation and despair -
providing unrivalled support, advice and hope.*

**Association of Young People
with ME Ltd**
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Company registration no. 03980311
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Who's Who



President: Esther Rantzen OBE

Chief Executive Officer: Mary-Jane Willows
Grants/Projects Officer: Katie James
Operations Manager: Wendy Holloway
Finance Officer: Marilyn Church
Membership Officer: Sue Webb

Advisors:

Medical: Dr. Nigel Speight (Consultant Paediatrician)
 Dr. Rashmin Tamhne (Consultant Paediatrician)
 Dr. Derek Proudlove (Consultant Child Psychiatrist)
 Dr. Colin Stern (Consultant Paediatrician)
 Dr. Betty Dowsett (Retired Microbiologist)

Education: Hilary Tandy (former Teacher)

Auditors: Baker Tilly

Board of Trustees - at the end of 2004.

Trustees voted on by the members of AYME.

Constitutionally, at least one AYME member and one parent must have a place on the Board.

Chairman: Jill Moss Founder of AYME. Retired teacher.
Treasurer: Paul Redwood Sales director IT firm. Father of AYME member.
Secretary: Geoff Long Retired personnel officer.
Trustees: Sarah Allen AYME member.
 Helen Brydges Teacher. Mother of AYME member.
 John Edwards C of E Minister. Pension scheme advisor. Father of AYME member.
 Kaye Redwood AYME member.
 Lindsey Stimpson Credit Controller. Mother of AYME member.
 Keith Whiting Retired businessman.

Co-opted Ann Lewis AYME member. P/T Teacher.
 Richard Moss Manager IT firm.

AYMEs Service Team Managers - at the end of 2004.

Drawn from, and voted on by the members of AYME. Job descriptions are written with other team managers consulting on the most appropriate candidate.

Gemma Ball: Fundraising Department
Sarah Barrie: OnLine Services
Helen Catling: Membership Services
Laura Gervaise: Special Services
Alison Grinham: Public Relations
Alasdair Leitch: General Services

Front Cover: Danielle, aged 10 years. Following six months in hospital, Danielle was able to move one hand and wave. She was awarded an AYME 'Special Achievement' award.



AYME has a year to be proud of

In this year's review you will be treated to a flavour of AYME's numerous activities and amazing achievements. As the months fly by we don't stop to think about all of the work being undertaken by our volunteers and staff team, so this is an opportunity to commend the "AYME family" for the incredible work it undertakes.

I remain in awe of our Young Service Managers – page 3. I am not aware of any other young volunteers who manage such large teams; rarely having the opportunity to meet face-to-face. They manage our 74 different member services and maintain a positive, up-beat and supportive environment for the volunteers.

Some 2004 facts:

- ✓ In total our volunteers worked an estimated 10,900 hours, paid at the minimum wage this would cost £50,000.
- ✓ 2004 has seen 500 new members join AYME – 25% increase on 2003.
- ✓ 60 media items in the papers, on radio or TV, raising awareness of ME and the support AYME can offer.
- ✓ 160,000 hits on our re-vamped web-site.
- ✓ 10% increase in members fundraising.
- ✓ AYME's team of medical advisors increased to 5, increasing the level and quality of information we can give to our members via the help-line.

2004 saw our Positive Living Project draw towards conclusion (pages 8 & 11). This project is very dear to my heart as it provided me with the opportunity to meet parents, carers and members across the country and to gain a greater understanding of their needs and wishes. Such has been the overwhelming interest in the project we plan to try to identify a new source of funding to ensure it can continue. Breaking the isolation for children in England, the project created a facilitator's guide, training video and CD which are now available for the 250 local ME groups around England, Scotland Wales and Northern Ireland. [A full report on this project is available from AYME].

Looking to the future there is still much to be done. The workshops and questionnaire have now given us a clear picture of what life is really like for a young person living with ME, their priorities, needs, their worries and quality of life. They provide evidence of the need for continued work in health, education and social services and they guide AYME on its future direction. 2006 will see AYME reach its 10th birthday and our theme for that year will be The Severely Affected. These members are often the forgotten ones when it comes to professional input, expertise and advice. We aim to run a campaign throughout the year to highlight their plight and increase both public and professional awareness of the spectrum of the illness.

Mary-Jane Willows. Chief Executive

History of AYME

8 years of Support and Growth

In 1995 five young people with ME met Jill Moss, a retired teacher also suffering from the illness. They encouraged her to write a self-help book - "Somebody Help ME" - which would explain the illness to them in an understandable and accessible form. Researching for the book, Jill found twenty-five more young people around the UK, isolated and lonely who wanted contact with each other. She communicated regularly with them and they gratefully nominated Jill for a BT/ChildLine award.

With the winner's prize money, a newsletter began and young members began to make suggestions as to the type of services they would like. With Jill's support, they were encouraged to run the areas themselves. **AYME had begun.**

A year later, in **October 1996**, the membership had risen to 350 and AYME [pronounced 'aim'] became a registered charity. A staff team was built as demand for advice and support escalated.

By the end of 2004, **3,400 young people** had been supported by AYME and more than **300 young members were volunteering** to work in the six service teams.

President's Support

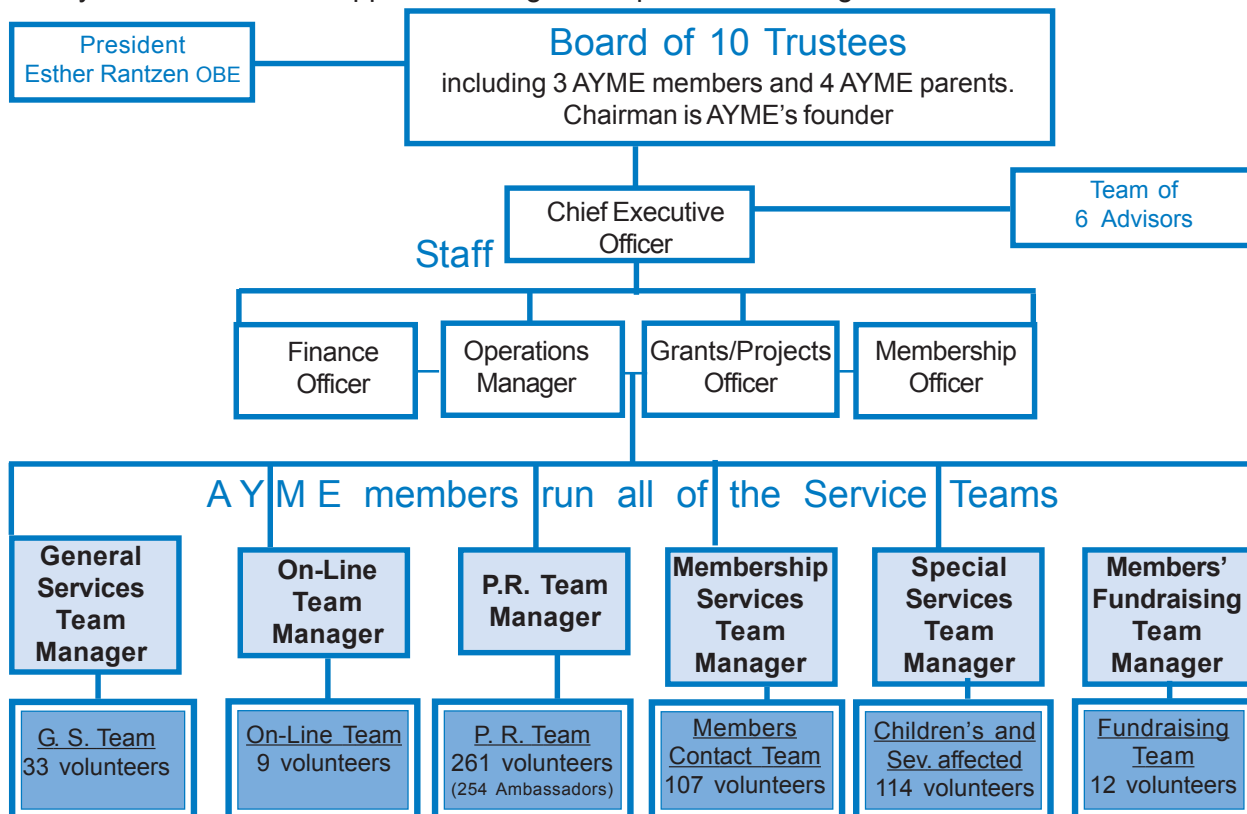
I am extremely proud to be President of AYME, for two reasons. Firstly, because I know it provides a unique support group and friendship circle for young people who would otherwise be isolated by their disabling illness. Secondly, because the knowledge and experience AYME gleans from the members and their families are passed directly to those who make decisions and need good information, for instance, providing crucial documents for clinicians, and assisting with the setting up of the new Department of Health ME centres.

Financially, AYME is an outstanding example to other charities, every penny being made to stretch miraculously far, every cost being cut to the absolute minimum. On principle, the membership of AYME has always been free, so that every child and young person who needs the service can receive it, whatever the family income. But that does mean that it depends on voluntary donations and company sponsorship, and the battle for funds is becoming ever more difficult. Anyone who has seen the pain and misery caused by this illness, as I have, will know how important AYME's work is. Please can I ask you to be as generous as possible, so that this work can continue.



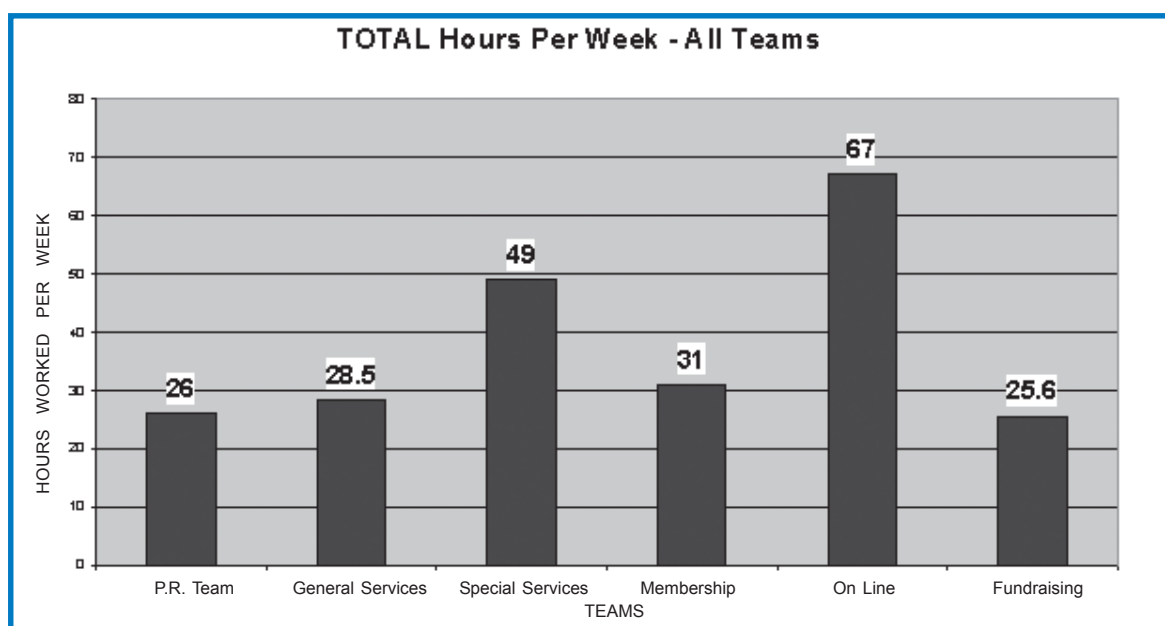
Structure of AYME

Three AYME members sit on the Board of Trustees while six AYMEs, voted in by the members, form the Service Team Managers. They manage AYME's six 'service departments' which include several dozens of co-ordinators who, in turn, manage their own team of volunteers. This structure is supported by 542 volunteers, of which over 300 are usually working for AYME and its members at any one time. All are supported through the Operations Manager in the office.



Young Volunteer Hours

All 300+ volunteers who work for AYME are sick children and young people, often combining their volunteer work with trying to catch up on their education. On average, the teams work a total of 227 hours in a week. Taking their illness into account, an average of 44 weeks in a year are worked, meaning a total of almost 11,000 voluntary hours - saving AYME over £50,000.



All the services - by members, for members

Over 300 young members of AYME run the day-to-day services, managing teams which they never see, and gaining friends whom they view as the very best friendships they have ever had.

General Services Manager



The General Services team includes 33 volunteers working in varied areas: Postal Libraries, Birthday Team and a free, bi-monthly Prize Draw.

The Birthday Team is made up of 1 Birthday Co-ordinator, who alerts her team of 24 of any newly joined members. Each of the 24 take their 2 week's turn to send out cards and small gifts to all members of AYME.

On-Line Manager



AYME's new, bright and informative web-site was launched in May 2004 receiving 6,000 hits a day in the first month.

Applauded for its professional and educational content it was put together entirely by the On-Line Team. Total hits in 2004 exceeded 160,000. A secure, members-only area with a message board, saw 30 new members join each month.

P.R. Manager



The PR team are responsible for 254 AYME ambassadors who live around the UK and are easily contactable when a fundraising cheque is needed to be received. Over 2004 the team worked in obtaining more than 60 media spotlights in newspapers, radio

and TV. They have also contacted many celebrities to gain their support and raise awareness.

Membership Services Manager



107 AYME members assist others to contact each other, breaking their isolation. 6 members assist in the contact services, such as pen-pals and email mates; 62 members around the UK volunteer as Regional Contacts for local support, whilst 39 sit on the

Members' Advisory Panel, acting in a consultative capacity for AYME's literature and assisting in the judging of members' competitions.

Special Services Manager



A total of 114 AYME members work with various responsibilities, in either the Children's Team or the Severely Affected Team. Many members make teddy bears for very sick

children whilst almost 100 team members are 'Bud-dies', who write regularly to severely affected members without expecting a reply. Others put together pages for AYME's bi-monthly magazine.

Members' Fundraising Manager



AYME members and their families raised in excess of £12,000 in 2004, that's a 10% increase over 2003. More than 100 events took place, such as hair shaving, coffee mornings, sale of home-made cards, and concerts; held to raise money for their beloved charity.

AYME graduates. This older group is run by a former AYME member, with a further 10 volunteers.



They are all over 26 years and can no longer be full members of AYME but wish for continued support and friendship. They produce a regular 12 page newsletter, have their own, on-line message board, fundraise and create awareness of AYME and ME. In 2004, 81 members paid a subscription for the services, with all profits going to AYME.

"We want to give something back for all that AYME has given us in our younger years." Liza

96% of AYME members believe that AYME understands their needs

AYME 's Mission

To:

- 1) **Empower children and young people with ME** to have a voice and present their own cases and take an active role in decisions about their lives.
- 2) **Promote peer advocacy and self-help** by replacing lost peer groupings.
- 3) **Campaign for increased recognition** and understanding of ME.
- 4) **Advocate** for parents in a crisis situation.
- 5) **Ensure services are run for and by children and young people with ME** and continue to meet their needs, within the resources of the organisation.

AYME is:

- **The largest national registered charity** supporting children and young people with ME, and their families.
- **A Whitbread award winning organisation** whose work with young volunteers has been celebrated and certificated.
- **A subscription-free organisation.** Free subscriptions allow equal and open access to our services.
- **A unique, 'family-feel' organisation** where the young person feels included and befriended.
- **A true membership organisation** where the members are actively involved in running the services within their charity.
- **An organisation which provides information** about the existence and diagnosis of ME for all members, professionals and families.
- **Bringing the rights of children with ME into the spotlight** through participating in Government working groups on education, health and social care issues.
- **Developing a large regional network** with an increasing number of members who are able to offer each other face-to-face support.

95% believe that AYME listens and responds to members' needs

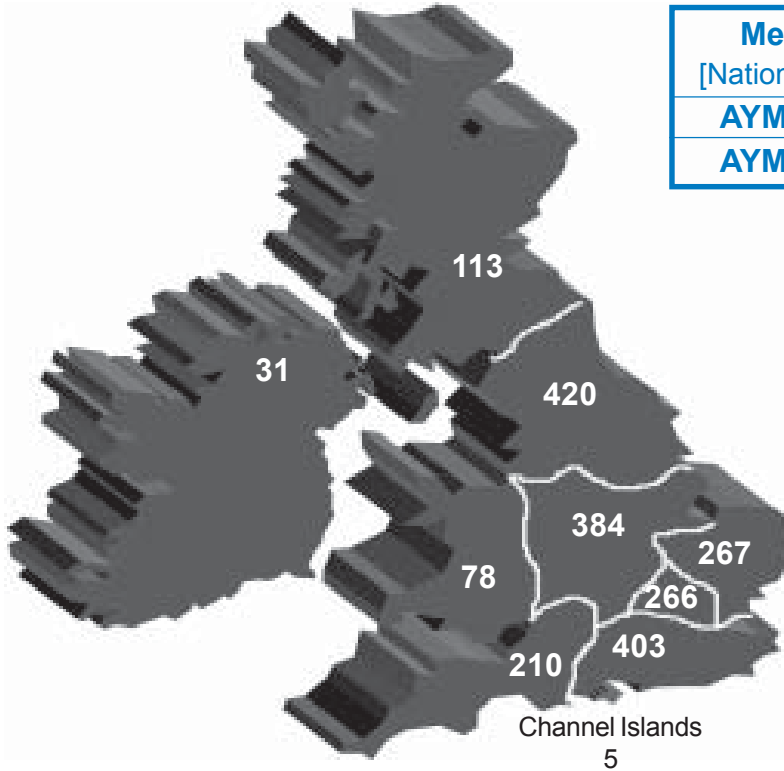
How many AYME members?

Over its 8 year history, AYME has supported a total of 3,420 children and young people.
Membership is from age 5 to 26 years.

Membership for 2004 = 2177 1722 Females - 455 Males

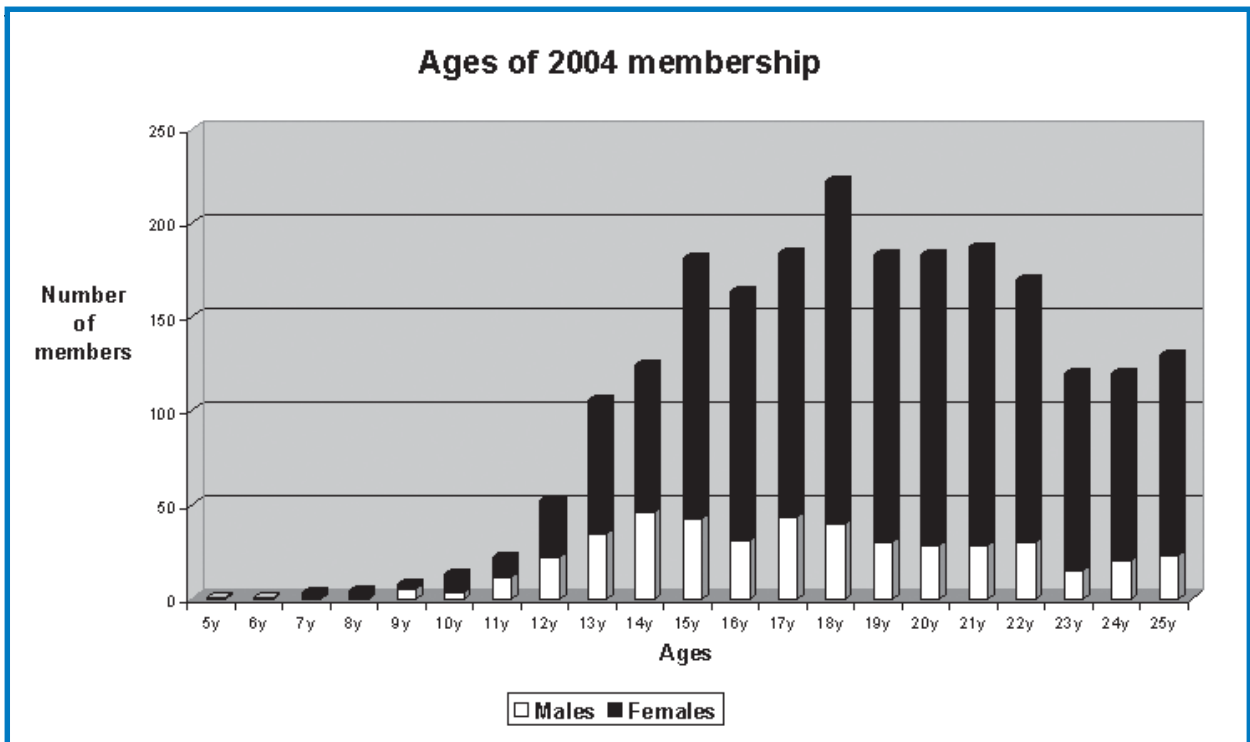
In 2004 AYME recruited over 500 new members - a 25% increase over 2003

In 2004 there was an increase in boys joining. Members ratio is now in line with national figures.



Members Ratio - Girls:Boys	
[National Ratio - 3 girls:1 boy have ME]	
AYME 2003	5.0 girls : 1 boy
AYME 2004	3.7 girls : 1 boy

FREE MEMBERSHIP
To enable open access to all, and a totally inclusive organisation, membership of AYME is free up to the age of 26 years. At this point, members are encouraged to remain as an AYME Graduate (p3)



Why do children
and young people
join AYME?

*"AYME gives
me support,
advice and
reassurance."*

*"Some big
girls who also
have M.E.
made me a
Teddy."*



*"CHEERS magazine is
a lifeline that appears on
my doormat every other
month."*

*"AYME is an
isolation breaker and
a friend maker."*

*"The best
support
system ever
for young
people with
ME."*

*"Meeting and
connecting with
others in a similar
situation is vital for
our sanity!"*

*"AYME
breaks the
horrible
isolation."*



AYME's 2004 postal survey told us:

“What we want from AYME is to continue with all the current services, but, please, in addition we need:”



- ◆ *More information on: medicines and ways of managing the illness.*
- ◆ *Practical issues such as travelling, employment, training, etc.*
- ◆ *Access to full-time advisors for education, medical issues, benefits, etc.*
- ◆ *Special attention to particular needs of the severely affected.*
- ◆ *A full-time support worker for AYME's army of volunteers.*
- ◆ *An increase in our Helpline opening hours.*
- ◆ *Some locally based support by someone who understands ME.*
- ◆ *Funds to train more Volunteer Peer Facilitators.*

“Our greatest problems are:”

- ◆ *Isolation*
- ◆ *Disbelieving doctors*
- ◆ *Dealing with the horrible symptoms*
- ◆ *Education*
- ◆ *Money problems*



AYME responds to its
members' needs

Responding to our Members' Needs

Reducing Isolation

'I feel so alone. Only AYMEs seem to understand.'

In 2004 AYME held one-day Positive Living Workshops, reaching out to 150 members and their families and carers as the workshop travelled around to 14 areas in England from Newcastle to Taunton. These workshops were led by young people with ME who had been trained as Volunteer Peer Facilitators. The day included a confidence boosting session with the participants learning a variety of strategies for communicating with doctors, family and friends, including eye contact, using the person's name, and preparing for the meeting in advance. A "sharing" session was included covering subjects like relationships, education, nutrition, sleep and pain management. This was followed by a relaxation session of breathing techniques, stretching and finally a creative session to give the young people ideas how to use their energy in a rewarding and productive way. A separate room was provided for the parents and carers to have their own "networking" meeting.

The achievements in the workshops far exceeded our expectations, achieving the aim of helping young people with ME to appear confident, even if they didn't feel it, and helped them express their needs to doctors, teachers, family and friends.

"I saw my doctor and used the tips for keeping calm and appearing confident. The appointment went well and I felt more in control."

"I wrote a letter to friends explaining exactly how ill I am and got positive responses and I'm even back in contact with my oldest friend."

Through the workshops, friendships were formed even though many had never met others with ME before, which boosted self-esteem, self-worth and motivation making the most out of life despite having a chronic disabling illness.

"It was really nice to know other people are going through the same things and be able to ask people in the same situation about any problems. One nice thing about AYME is that total strangers are so nice and understanding of your problems. We all found that at the workshop."

Young people with ME and their parents/carers formed new networks and some volunteered to organise other meetings and social meet-ups with videos and role-play events. In between meet-ups, AYMEs and parents agreed to keep in touch via email, letters, AYME's website message board and occasional social meet-ups.

The workshops were made possible through grants from the Department of Health, Awards for All and Lloyds TSB Foundation for England and Wales.

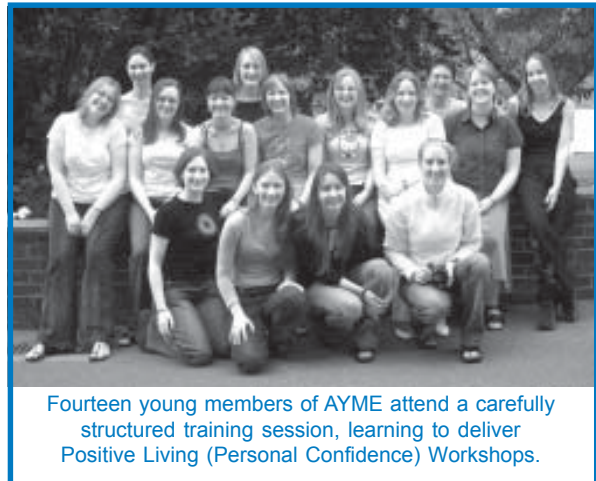
AYME needs funding to continue the workshops and train more young people to run them.

Education - *'my friends don't understand.'*

√ Our Education Advisor has taken part in research for various organisations, reporting for journalists and assisted in the writing of a script for the BBC series, 'The Doctors'. Articles have been written for the members' magazine 'Cheers', and the parents' news bulletin 'Link', such as advice to teachers when members wish to make a smooth transition back into school from home tuition.

"LINK has been an invaluable source of advice for us." Mother of 16 year old.

√ During 2004, bids were submitted for AYME to up-date the schools video education pack. At the end of the year (2004) the **Children's Fund** awarded AYME £6,650. A film crew are presently producing a short video which will help to educate the peers of our members.



Fourteen young members of AYME attend a carefully structured training session, learning to deliver Positive Living (Personal Confidence) Workshops.

Responding to our Members' Needs

Disbelieving doctors - 'My doctor doesn't seem to know how to help.'

AYME has worked with the Royal College of Paediatrics and Child Health for three years on a Lottery funded project. In December 2004, Clinical Guidelines on ME were sent to every Paediatrician in the UK, together with a leaflet for patients. Ayme chaired the sub-group which developed the patient leaflet, ensuring that the child's voice was heard. It is expected that both documents will have a positive effect on doctors' understanding of ME.

"I think the Patient Leaflet is great. If my GP gives it to each of his patients, I know they will feel they are being taken seriously, and that he understands their illness."

Lorna



Dr. Stephen Ladyman, Health Minister, speaks at the launch of the Royal College's Guidelines on ME at the Houses of Parliament, in front of Ayme members, clinicians and politicians.

Dealing with the symptoms - 'The pain is horrible, what can I do?'



AYME Help-Line. Open each weekday for four hours: 10 am - 2 pm

AYME is an associate member of the Telephone HelpLine Association.

- ✓ The HelpLine received 3,500 calls into the office and a further 170 telephone calls to our educational advisor and over 50 to the home of our Parent Contact volunteer. The busiest month was September, with 400 calls. Many of these calls were concerned with children and young people having increased symptoms at the start of school/college term.



"You're the only helpful person I've spoken to about this. Thank you so much." Mother of 13 yr old

- ✓ The Help-Line staff have written information sheets on frequently asked questions, allowing a summary of advice to be sent to each caller following the phone conversation.
- ✓ Claire, who has experience of being very ill, has written a 30 page 'Survival Guide for the Severely Affected', with support and advice from our Help-Line staff.

"Thank you for writing Surviving Severe ME. It's an excellent piece of work which I've found useful both as a GP and a parent of a Severely Affected boy - tube fed for over 3 years."



- ✓ A total of 1,100 information packs were sent out to callers. A significant amount of information can also be found on Ayme's web-site: www.ayme.org.uk
- ✓ 40% of members' parents are registered with our Parent Contact Co-ordinator for support.

Money problems - 'How do we go about applying for benefits?'

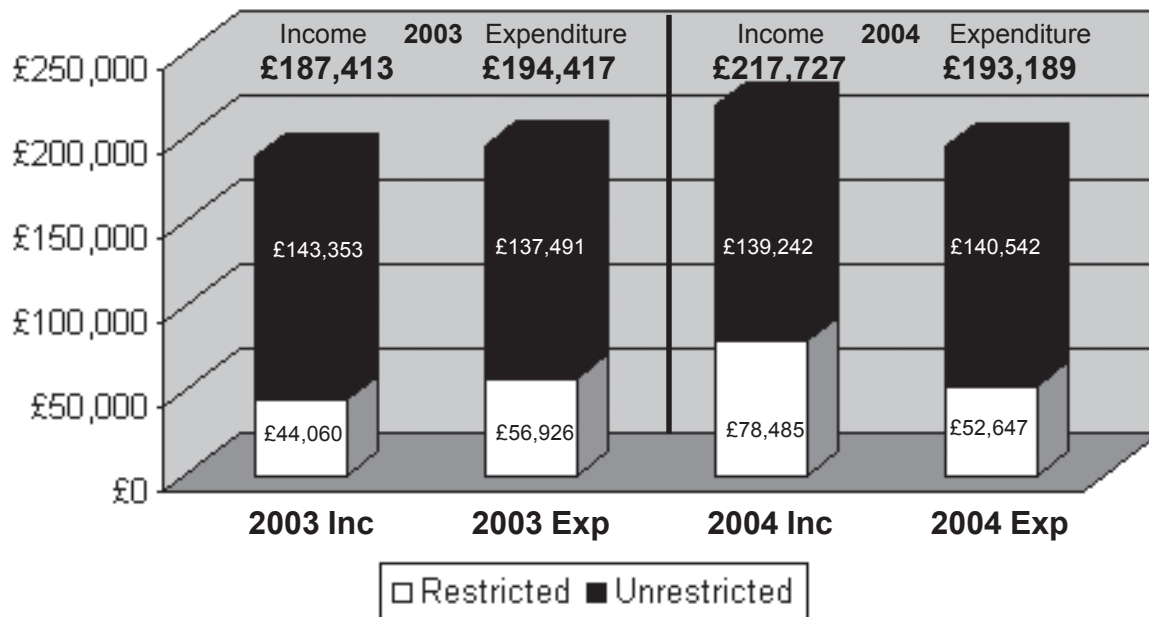
- ✓ Ayme has written and published a comprehensive guide to accessing Disability Living Allowance. The content was developed through the experience of Ayme's HelpLine staff, Ayme members and their families, and the Benefits' Office.

"Thank you for sending me the excellent DLA booklet. It was so understandable and made the job much easier for us to fill in the forms. We now await the decision!" Sam

AYME continues to research opportunities to respond to members' needs.

Finance

Income and Expenditure 2003 and 2004



Incoming resources for the year were £217,727 (2003: £187,413) compared with resources expended of £193,189 (2003: £194,417), giving a surplus of £24,538 (2003 shortfall £6,980). This surplus was entirely accounted for by restricted funds where grants were received in advance of related expenditure. For AYME's unrestricted funds, income and expenditure were closely balanced.

AYME charges no membership fee to its members and is therefore heavily dependent on donations and members' fundraising for its unrestricted income. Income from this source was some 10% higher in 2004 than in 2003. In addition, membership fees to LINK, the newsletter for parents and carers, contributed more than £12,000 (£nil in 2003).

There was no Conference in 2004 with the result that unrestricted income and expenditure were both some £25 – 30,000 lower than they would otherwise have been. After adjusting for this item, the increase in unrestricted income was sufficient to cover increased costs arising from expanded services to members and from decisions on staffing and other overheads required to maintain AYME's current scope of activities.

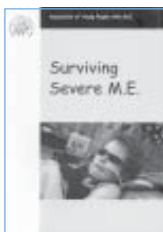
The Trustees continue to exercise tight control over expenditure and have not undertaken major new projects until sources of funds have been identified.

For a more detailed financial breakdown ask for the 2004 Report and Accounts.

Major Achievements of 2004

Survival Guide for the Severely Affected

AYME was very proud to publish this book, edited by 21 year old AYME member, Claire Wade, who is severely affected herself. This excellent book includes advice and guidance on daily strategies together with factual information to help those trying to cope at this end of the functional ability scale.



Guidelines for Paediatricians and a leaflet for young people



After months of hard work and determination the Royal College of Paediatrics published Guidelines for Paediatricians together with an information leaflet for patients. AYME members, a parent and our Chairman played a vital role in ensuring the voices of our children were fully represented throughout the guidelines.

CFS/ME Exemplar: DoH

AYME sat on the steering group for the Department of Health's National Service Framework for children, which provides guidance for GP's dealing with all long-term chronic illnesses. The Exemplar follows the care pathway of Megan, 14 years old, from the onset of symptoms through to her diagnosis of CFS/ME and on-going care.



National Support Worker (NSW)



After numerous attempts AYME was finally successful in its bid to Children in Need to provide members with a National Support Worker. Working alongside our help-line team and parent co-ordinator, the NSW will provide additional support to members and families in times of crisis. We hope to appoint this post in spring 2005.

At a time when circumstances can be overwhelming for our members and their carers, this post will help families to communicate their needs to professionals in health and education settings. Unfortunately some disbelief and suspicion continues to surround CFS/ME and this new post will help us to do further work to educate and inform.

New DoH Centres for CFS/ME

Mary-Jane Willows (CEO) has been involved initially in the bids and then in the development of several of the new DoH services for CFS/ME in England. There are 13 new Clinical Network Co-ordinating Centres and 52 Local Multi-disciplinary teams who, over the next three years, will continue to develop services. An AYME member from Bristol is representing children and young people in the South West and it is hoped that in 2005 Mary-Jane will be able to introduce more members to take on this important role. Our medical advisors are actively involved in the CNCC's work and members are kept informed about development of this work through the pages of LINK, a bi-monthly news bulletin for parents, carers, professionals and AYME members over 18y.



LINK Associates

LINK Associates was launched in 2004. This new service, funded by a membership fee, provides a bi-monthly news bulletin giving information on research and education, has a parents page and up-dates on any new developments in the world of CFS/ME. In 2005 a web-site dedicated to LINK members will be provided.

Work in the research field

Jill Moss, our founder and Chairman, has given much of her own time as a volunteer to support and consult on several pieces of research. Working with over 300 AYME members she developed a Functional Ability Scale for young people. This work will be published in the Journal of Child Health in March 2005.



An AYME parent has carried out social psychology research using the AYME message board to identify the members' need for social inclusion; whilst the University of Central Lancaster has interviewed members and their families asking for their experiences of the Health Service - due to report during 2005.

AYME's marketing leaflet

To help us raise much needed funds a new marketing leaflet has been produced. Professionals with a marketing and design background donated their time to this project. The cover shows the harsh reality of severe ME with a black and white photo of one of our SAM's; inside is a delightful photo of Eden who at the time was our youngest member aged just 5 years old.



Thanks to the following:

The biggest “Thank you” goes to ALL our members and their families and friends for the fantastic fundraising efforts throughout the year every year. Every penny counts here at AYME.

“Thank you” also goes to all the schools, Rotary Clubs, Inner Wheels, Lions’ Clubs, Rowing Clubs, Cycling Clubs, all our riders in the A to B summer cycle challenge and many other clubs and organisations that raise funds for AYME.

A special “Thank you” to those families and friends who make donations to AYME in memory of a family member or colleague; to all our supporters that have set up Standing Orders; and to those who have donated on line at www.ayme.org.uk

Thank you to:

Awards for All: North East, East Midlands, North West, South East and South West.

All our LINK members.

Barclays Bank Business Banking

BBC Children in Need

Co-operative Group Central and Eastern Region

Department of Health

Fayyaz and Sarah Chaudhri

International Woodwork Exhibition

John and Judith Edwards of William Fishwick and Son Ltd

Lloyds TSB Foundation for England and Wales

National Extension College

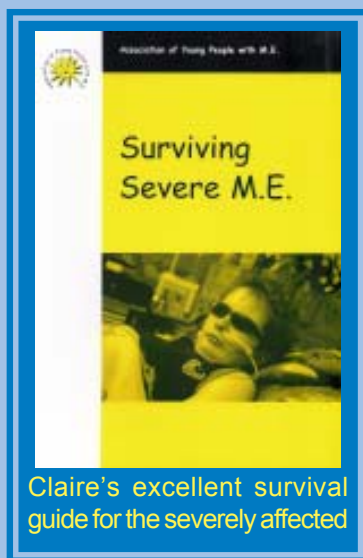
Milton Keynes Community Foundation Children’s Network Fund



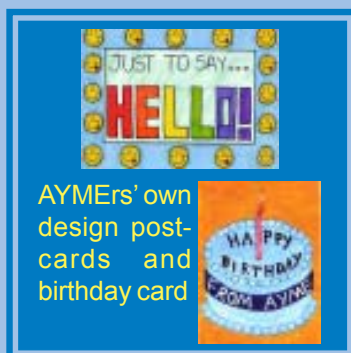
Special thank you to our volunteers:

Rachel Green and her family for packing ‘Cheers’ and ‘LINK’ magazine every two months;
Tim Huxford Design for the excellent design and layout work in AYME literature and LINK.
John Moss for his time in filming and editing events for AYME;
Beryl Dawson for her regular weekly appearance to do admin tasks in the office;
All the AYMEr volunteers and the Board of Trustees for their time and energy.

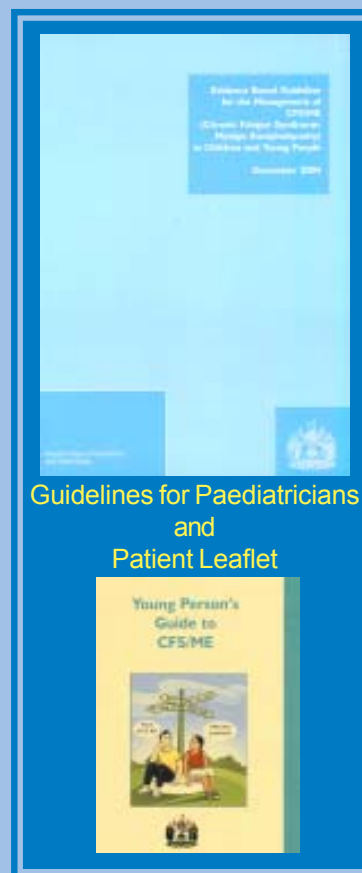
AYME's own publications and those in which AYME has had significant input over 2004



Claire's excellent survival guide for the severely affected



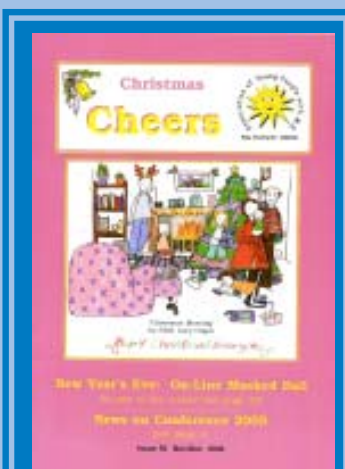
AYME's own design postcards and birthday card



Guidelines for Paediatricians and Patient Leaflet



Functional Ability Scale



CHEERS the members own bi-monthly magazine



AYME's Marketing Leaflet



LINK - the parents/carers bi-monthly magazine



CFS/ME Exemplar

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Printed by Aztech Creative Print, Milton Keynes
 01908 649555