



**CMT United Kingdom**

**Annual Report  
and Accounts  
2005**

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# Welcome to the Annual Report for the year 2005 from CMT United Kingdom

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# Executive Committee Report 2005

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2005 proved to be another busy year for the Executive Committee, with a Co-ordinators meeting, a Welsh Regional Conference, Young People's Weekend and various other projects alongside the usual activities such as the Annual Conference. A lot has been achieved, including work that will have lasting benefit.

## Highlights of the Year

**The AGM and Conference** were held on 23rd April at the Holiday Inn, Runcorn, Cheshire. About 120 members attended, and we had speakers from the Walton Centre in Liverpool talking about pain issues, and an Occupational Therapist, among others.

**The Welsh Regional Conference** was held on 9<sup>th</sup> July in Cardiff. 50 members and family attended from across the region to hear speakers on Management of CMT, and Genetic issues. Our thanks to Margaret Read, whose donation made this event possible.

**The Young People's Weekend** was held in September 2005. The event was heavily over-subscribed for the first time, so some youngsters were unable to attend. Feedback from the last two events of this type show that we really must not underestimate the difference this event makes to the people attending. All enjoyed it greatly, forming new friendships. But more importantly, they grew in confidence and independence over the weekend. The opportunity to spend time with others with similar problems, and to experience new challenging activities together, helped all to explore their abilities without fear.

## Membership

Membership has continued to increase. In 2005, we saw a slight decrease in new memberships: 133 (139 in 2004), whilst new enquiries were up by 100 on the previous year, to 450. The total membership in the UK was 1256 as at 31<sup>st</sup> December 2005. In addition to this we mail to 128 professionals and 65 international members.

A new membership database, purchased in February 2005, has already proven to be far more flexible and user friendly than the previous software. Storage and retrieval of data and administrative tasks like mail outs are all much simpler and faster, easing the Secretary's job and freeing up more time to invest on other activities to help support members.

## Care and Support

The new version of "Living with CMT" was sent to all members during early 2005, and has been extremely well received. We were delighted to achieve the "CHIQ" mark for excellence, clarity and relevance from the Centre for Health Information Quality – a real feather in the cap for our publication.

The rewrite of our book "Charcot-Marie-Tooth: A Practical Guide" began in 2005, with a May meeting of a focus group drawn from the committee and membership, together with John Isitt, from Resonant Media Ltd, who is undertaking the re-write for us. This focus group's remit is to ensure that the book contains as much relevant information as possible, presented in a format that is both useful and easy to read.

CMT United Kingdom is a member of a number of organisations, including the Neurological Alliance, NCVO and the LMCA (formerly known as the Long Term Medical Condition Alliance). We continue to support the work of the Neurological Alliance and LMCA to ensure that the National Service Framework for people with Long Term Conditions (launched in March 2005) is implemented in full. We also joined the World Muscle Society and now receive up to date research papers as published in their monthly magazine.

In June 2005 we decided to host an International CMT Convention in April 2007, which will mark the organisation's 21<sup>st</sup> Anniversary. This will be an excellent opportunity for our members to meet and socialise with members from other CMT organisations from abroad and for all to learn more from the professionals attending. Information will be published in ComMenT and on the website once available.

## Marketing and Fundraising

ComMenT, our quarterly magazine, continued to be a popular method of keeping in contact with our membership. In 2005 Julia Gilbert, recruited through the charity Reach, took over from Rosie Croucher as Newsletter Editor. We continued to offer ComMenT electronically during the year, a move that has proved popular with just over 200 members now receiving it this way. This allows us to continue vital services, whilst actually reducing costs.

*"Working to support those who are affected by Charcot-Marie-Tooth Disease, also known as Hereditary Motor and Sensory Neuropathy or Peroneal Muscular Atrophy."*

In 2005 we began a major overhaul of the website, to improve the information on the site, incorporating the ability for frequent updating, and upgrading the level of user accessibility. Construction began in Autumn 2005 and a "test" version of the new site launched on [www.cmt.org.uk](http://www.cmt.org.uk) in late December. Launch of the full working version, to include online donations, memberships and subscriptions, news, forums and a small shop is scheduled for January 2006.

## **Governance**

The conversion of CMT United Kingdom into a company limited by guarantee was approved at the AGM by a large majority and completed in 2005. The new company "CMT United Kingdom" was registered at Companies House on 26<sup>th</sup> September 2005. The change also involved a new charity being registered with the Charity Commission, achieved in December 2005. The original charity number 327981 will be dissolved as soon as all the transfers are completed. Our grateful thanks to the solicitors at the Clifford Chance Partnership in London, who did all the work for us on an entirely voluntary basis.

The Executive Committee would like to acknowledge the invaluable contribution to the organisation of two departing Trustees – Karin Rodgers for being an excellent, and sometimes hilarious, Chair during the past three years, and Rosie Croucher for her excellent work as Newsletter Editor. We were very pleased to welcome David and Pat Golder to the Committee - particularly as Dave took on the onerous task of Treasurer! Lisa Welsh was also elected to the committee.

## **Research**

Karen Butcher attended a European Neuromuscular Centre (ENMC) Workshop in Holland in April. The purpose of this workshop was to agree a research protocol for a project exploring the effectiveness of Vitamin C in treating the symptoms of CMT Type 1a. Dr Mary Reilly will head the clinical trial in the UK and CMT United Kingdom committed £6000 to this (to go to the National Hospital early in 2006), for equipment required during the project, which could also aid future projects by establishing ways to assess the impact of drugs trialled. Our thanks go to Dr Mary Reilly for including Karen in this Workshop, and to the ENMC for funding the trip.

## **Local Groups**

We now have 11 groups across the UK, providing additional contact and support to members. A successful Co-ordinators meeting was held in October, in Coventry. The majority of Co-ordinators attended, together with several committee members, and it was a successful forum for the exchange of ideas and information. Several people attended who have not yet formed their groups – in South Wales and West Sussex - but were able to leave the meeting inspired to get their groups off the ground when their time permits.

## **Finance**

The gross income for the year was £43,277.00 - down on the previous year. With expenditure up, at £69,612.00, we had a deficit of £26,335.00 for 2005, which meant dipping into our reserves. This may sound drastic, but the extra outlay funded projects that will greatly improve member services and support to people with CMT, and aid administration, including major one off projects. We implemented a brand new look, up-to-date website. With the introduction of WorldPay, the processing of subs and donations is now much easier. It is also expected to generate extra business over the next few years, thus making the website virtually self financing. Other significant expenditure included the initial payment for the second edition of our book "Charcot-Marie Tooth – A Practical Guide", as well as the production and accreditation of the new "Living with CMT" booklet.

The Grand Prize Draw 2005 made £2829 profit, including over £1450 in donations. As we are still waiting on the processing of Gift Aid donations from the Inland Revenue for 2004/5, we expect at least another £3,000 income, which will be added to our 2006 accounts. We have submitted funding bids to a number of small Trusts and will hear back in 2006. Other bids are planned and we have implemented a tight financial budget for 2006.

## **Conclusion**

2005 has been a good year, with many achievements. 2006 will bring us the completion of our book and a Scottish Conference, funded by a grant from Awards for All Scotland. With the reduction in income during 2005, and the need for a tighter financial budget for 2006, your help in raising funds and/or awareness of CMT United Kingdom will be more appreciated than ever. Our priority is to meet the needs of our membership and we appreciate the involvement of our membership, at conferences, local group meetings and by your letters, phone calls and contributions to ComMenT.

*"Working to support those who are affected by Charcot-Marie-Tooth Disease, also known as Hereditary Motor and Sensory Neuropathy or Peroneal Muscular Atrophy."*

# STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31ST DECEMBER 2005

	Note	Unrestricted Funds £	Designated Funds £	Restricted Funds £	Total Funds 2005 £	Total Funds 2004 £
<b>Income and Expenditure</b>						
<b>Incoming Resources</b>						
Donations, Subscriptions and Similar Incoming Resources	2	26,451	-	-	26,451	32,387
Income from activities in furtherance of charitable objectives		4,253	9,245	1,480	16,205	25,335
Investment Income		1,848	-	-	1,848	1,789
		<b>32,552</b>	<b>9,245</b>	<b>1,480</b>	<b>43,277</b>	<b>59,511</b>
<b>Resources Expended</b>						
Charitable Expenditure:						
Costs of activities for charitable purposes	3	14,063	11,463	13,732	39,258	20,069
Support Costs	4	29,400	-	-	29,400	23,170
Management and Administration	5	954	-	-	954	573
		<b>44,417</b>	<b>11,463</b>	<b>13,732</b>	<b>69,612</b>	<b>43,812</b>
<b>Net (Outgoing)/Incoming Resources before Transfers</b>						
		<b>(11,865)</b>	<b>(2,218)</b>	<b>(12,252)</b>	<b>(26,335)</b>	<b>15,699</b>
Transfers between funds		-	-	-	-	-
<b>Net Movement in Funds</b>						
		<b>(11,865)</b>	<b>(2,218)</b>	<b>(12,252)</b>	<b>(26,335)</b>	<b>15,699</b>
Balances brought forward at 1st January 2005		37,638	12,221	21,688	71,547	55,848
Balances carried forward at 31st December 2005		25,773	10,003	9,436	45,212	71,547

**The financial information in this summary has been extracted from the Charity's statutory accounts that were approved by the Board of Trustees on 4th March 2006. The statutory accounts have been audited, without qualification, and submitted to the Charity Commission. Copies of the full accounts are available from PO Box 5089, Christchurch, BH23 7ZX**

## BALANCE SHEET AS AT 31ST DECEMBER 2005

	Note	2005		2004	
		£	£	£	£
<b>FIXED ASSETS</b>					
Tangible Assets	8		-		-
<b>CURRENT ASSETS</b>					
Stocks		1,738		7,095	
Prepayment		-		-	
Cash at Bank		43,166		65,433	
Cash in hand		100		350	
Monies Held by Local Groups		1,468		-	
		<u>46,472</u>		<u>72,878</u>	
<b>CURRENT LIABILITIES:</b>					
Amounts falling due within one year	9	1,260		1,331	
			<u>45,212</u>		<u>71,547</u>
			<u>45,212</u>		<u>71,547</u>
<b>Represented by:</b>					
Unrestricted Funds	10		23,189		37,638
Designated Funds	10		10,503		12,221
Restricted Funds	10		11,520		21,688
			<u>45,212</u>		<u>71,547</u>

## NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31ST DECEMBER 2005

	Unrestricted Funds £	Designated Funds £	Restricted Funds £	Total Funds 2005 £	Total Funds 2004 £
<b>2. INCOMING RESOURCES</b>					
Gross bank interest	1,848	-	-	1,848	1,789
Subscriptions	10,817	-	-	10,817	8,874
Donations	15,634	-	-	15,634	23,513
Grand Prize Draw	-	3,588	-	3,588	3,297
Sales Goods	2,984	-	-	2,984	2,885
Research	-	-	60	60	793
Welsh Conference	-	-	599	599	-
Bookings:					
Annual General Meeting	-	2,670	-	2,670	2,893
Young Persons Weekend	-	-	-	-	640
Events for children	-	-	-	-	500
Local Groups	-	-	821	821	5,475
Sundry income	-	-	-	-	1,789
"200" club	-	2,987	-	2,987	1,538
Gift Aided Donation	398	-	-	398	1,891
Gift Aided Subscriptions	871	-	-	871	3,634
	<b>32,552</b>	<b>9,245</b>	<b>1,480</b>	<b>43,277</b>	<b>59,511</b>
<b>3. COSTS OF ACTIVITIES FOR CHARITABLE PURPOSES</b>					
Items for re-sale (adjusted for stock)	5,759	-	-	5,759	3,277
Welsh Conference	-	-	1,438	1,438	-
Young Persons Weekend	-	-	4,008	4,008	-
Events Held	-	-	-	-	206
Grand Prize Draw	-	1,137	-	1,137	944
Local Groups	-	-	2,295	2,295	2,704
"200" Club	-	2,383	-	2,383	450
Project Book Expenses	-	-	5,991	5,991	-
Annual General Meeting	-	7,943	-	7,943	5,276
Travel, Subsistence and Accom.	7,465	-	-	7,465	7,212
Co-ordinators Meeting	839	-	-	839	-
	<b>14,063</b>	<b>11,463</b>	<b>13,732</b>	<b>39,258</b>	<b>20,069</b>
<b>4. SUPPORT COSTS</b>					
Publicity	203	-	-	203	2,541
Training	582	-	-	582	919
Newsletter	3,802	-	-	3,802	7,114
Telephone	441	-	-	441	466
Postages	3,507	-	-	3,507	2,743
Stationery	841	-	-	841	1,140
Leaflets	4,031	-	-	4,031	3,156
Insurances	1,446	-	-	1,446	1,293
Storage Facilities	945	-	-	945	675
Rent	2,200	-	-	2,200	-
Computer Costs	5,026	-	-	5,026	2,381
Website Costs	4,787	-	-	4,787	-
Consultancy Fees	843	-	-	843	-
Subscriptions and memberships	601	-	-	601	306
Sundries	145	-	-	145	436
	<b>29,400</b>	<b>-</b>	<b>-</b>	<b>29,400</b>	<b>23,170</b>

5. **MANAGEMENT AND ADMINISTRATION OF THE CHARITY**

	Unrestricted Funds	Designated Funds	Restricted Funds	Total Funds 2005	Total Funds 2004
	£	£	£	£	£
Bank Charges	372	-	-	372	73
Accountancy	582	-	-	582	500
	954	-	-	954	573

6. **STAFFING** The Charity had no employees during the year.

7. **TRUSTEES AND RELATED PARTIES** No remuneration was paid to committee members during the year. Expenses of £5,478 were reimbursed to 10 committee members during the year in respect of costs incurred by them for postage, stationery, telephone, travel subsistence and accommodation whilst acting on behalf of the Charity. There are no related party transactions of which the committee are aware.

8. **TANGIBLE FIXED ASSETS**

<b>Cost</b>	<b>Equipment £</b>
At 1st January 2004 and 31st December 2005	3,524
<b>Depreciation</b>	
At 1st January 2005	3,524
Charge for year	-
At 31st December 2005	3,524
<b>Net Book Value</b>	
At 31st December 2004	-
At 31st December 2004	-

<b>CREDITORS: Amounts Falling due</b>	<b>2005</b>	<b>2004</b>
<b>Within one year:</b>	<b>£</b>	<b>£</b>
Bank Overdraft	-	-
Other Creditors	-	-
Accruals and Deferred Income	1,260	1,331
	1,260	1,331

10. **FUND ANALYSIS**

	Income £	Expenditure £	Surplus/ (Deficit) £	Brought Forward £	Fund Transfers £	Carried Forward £
<b>Unrestricted Fund</b>						
General Fund	32,552	44,417	(11,685)	37,638	(2,584)	23,189
<b>Designated Funds</b>						
"200" Club	2,987	2,383	604	3,161	-	3,765
Annual General Meeting	2,670	7,943	(5,273)	-	2,951	(2,322)
Local Groups	-	-	-	-	-	-
Grand Prize Draw Fund	3,588	1,137	2,451	9,060	(2,451)	9,060
	9,245	11,463	(2,218)	12,221	500	10,503
<b>Restricted Funds</b>						
Special Projects Fund	-	5,991	(5,991)	7,578	-	1,587
Research Fund	60	-	60	7,019	-	7,079
Young Persons Weekend	-	4,008	(4,008)	2,763	1,245	-
Children's Website	-	-	-	815	-	815
Welsh Conference	599	1,438	(839)	-	839	-
Events Fund	-	-	-	319	-	319
Local Groups	821	2,295	(1,474)	3,194	-	1,720
	1,480	13,732	(12,252)	21,688	2,084	11,520
<b>Total Funds</b>	<b>43,277</b>	<b>69,612</b>	<b>(26,335)</b>	<b>71,547</b>	<b>(0)</b>	<b>45,212</b>

# COMMITTEE 2005

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## Chairman

Mrs Karin Rodgers (to April 2005)  
Mrs Leonie Jones (from 2005)

## Vice Chairman

Mrs Rosemary Croucher (to April 2005)  
Mr Howard Cohen (from April 2005)

## Treasurer

Mrs Leonie Jones (to April 2005)  
Mr David Golder (from April 2005)

## Committee Members

(from April 05)

Miss Sarah Fletcher

Mrs Pat Golder

Mrs Annette Masser

Mr Stephen Thorpe

(from April 05)

Mrs Lisa Welsh

## Secretary

Mrs Karen Butcher  
PO Box 5089  
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**CMT United Kingdom**



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Registered Charity  
No. 1112370