

Introduction from our Chairperson, Olav Skretteberg

We are very pleased to extend a warm welcome, and say 'thank you' for attending the 2011 Annual General Meeting of Tourette Scotland. This has been another year of change, development and progress; thanks to the continuing dedication of staff, volunteers, trustees and advisors. We have concentrated on establishing new services, increasing support for our members, and undertaking more 'face to face' work with individuals, so we can focus our efforts on the most pressing needs.

We are now revising our Business Development Plan for 2012 – 2015; evaluating achievements this year, setting out new strategies and continuing our efforts to influence national policy and increase the availability of services for those with TS.

Our main achievements include:

- An office move to larger, more suitable premises to increase our service provision, make way for future developments and improve accessibility for visitors
- Increased core membership and more professional contacts
- Increased our range of support for professionals, directly working with practitioners to instil knowledge about Tourette Syndrome and enhance the working practices for TS
- Collaborated with major funders to target our future work and support them to deliver their objectives
- Participated in lobbies for inclusion, and assisted with benefits, education and employment
- Instigated a National Helpline with a dedicated 0300 number and extended hours
- Devised new, well researched resource materials; including bespoke information packs
- Set up a forum, blog and extended the output of our website through the Web Information pilot
- Piloted an external training programme and outreach facility that is flexible and meets individual needs
- Established a data retrieval system with review functions that will help to define our future work
- Set up interactive services for harder to reach individuals
- Welcomed a new Support Group
- Hosted some very successful 'road shows'; keeping Tourette Scotland in the public eye

The current economic climate has brought about service cuts which affect our members, and so Tourette Scotland will do what we can to alleviate the impact. In the year ahead, we plan to add to service provision and continue to work closely with practitioners; but we cannot change our purposes to replace lost public services.

Undoubtedly, the aims of Tourette Scotland cannot be achieved without securing a sustainable revenue income. Funding opportunities are fewer, and for Scotland, a large tranche of national funding is earmarked for UK-wide initiatives such as the London Olympics. Children In Need allocates their grants very carefully, and so we are working closely with them to achieve best value for their investment. We are grateful for their continued assistance which has helped us to retain our core services. We look forward to next year with the prospect of extending this further. Other funders who have given us invaluable support have been the Robertson Trust, and Lloyds TSB. Both have been involved in reviewing our work and shaping future initiatives.

Tourette Scotland prides itself in being a 'learning organisation' at the forefront of innovation, promoting positive change and progress. Whilst some stakeholders may disagree with our approach at times, in those instances we do welcome different points of view and alternative perspectives. Indeed, we view such challenges as helpful to a critical re-evaluation of what we do, and how we do it. New ideas undoubtedly help us to sustain the progressive and worthwhile aspects of our work.

Whilst this report is concerned with our achievements this year, we do keep a keen eye on the future. Much of our recent work has been designed to underpin future plans and sustain our achievements in the longer term. Next year we are looking forward to hosting a national conference, increasing membership support, and building on those vitally important practitioner partnerships. I wish to conclude by expressing my sincere gratitude once again to everyone, who in their various ways has contributed to the continued and growing success of Tourette Scotland; as a leading authority and a valued support to everyone who lives with, and experiences the challenge of Tourette Syndrome.



Olav Skretteberg Chair – Tourette Scotland 29th October 2011

Report from JUDY BARROW, Development Manager:

If my first year was hectic, the second year has proved more so, but wholly rewarding. Our members have taken part in conferences and have contributed to a range of publications as well as the usual media. The face of Tourette Scotland includes many people who work hard on its behalf. Thank you.

A workshop with our Trustees in January has resulted in a series of pilot projects, including Outreach, Web Development, External Training and Data Retrieval. The Trustees and our Chair, Olav Skretteberg, have been invaluable in supporting the development role. In addition, colleagues Lauren Strachan, Ruth Smith, Chris Achenbach, Janice Mylan, Mark Lincoln and Tony Lambert have shown that a strong core team is essential. Whatever my role says it is, it's not possible without the interweaving of expertise and skills from others. In addition, our support leaders and group volunteers have contributed invaluable time, experience, resources and support.

With this weave of strong threads, we can sustain our work and move forward with the aim of developing Tourette Scotland's work to befit the identified needs of the TS community. Our activities, research, relationships and resources have been tested, tried, pored over and revised, with such as the Factsheet proving popular, as is the new resource pack for schools. The new training programme has been welcomed and in particular the peer sessions, which have helped our children to explain their condition to others and for some, it's proved a way to gain acceptance.

There are still gaps in information provision, and again, our support services have shown that without Tourette Scotland and its team of staff, volunteers and advisors, this gap would be very wide indeed. As such, a lot of my work this year has been to assess where people living with TS are finding difficulties, ideas for new services, and to work with those who can help us to overcome barriers. A significant number of practitioners who are in touch with us are primary care workers, social workers, education psychologists, doctors, support agencies and advice service representatives. They are the ideal target audience for our awareness-raising, and by ensuring that they have good information, also for building up burgeoning partnerships.

We are working on a bespoke pack of information for these practitioners, especially the neurologists, (for whom nothing bespoke in Scotland exists) with the support of our medical advisors. We can see the scope of this in terms of working within the medical system via the Pathways programme and this will also include research that will filter into European-wide management guidelines, and to ensure that Tourette Scotland is a key contributor. This is essential, so that we remain at the forefront of developments in the TS world.

The information mailshot programme shows that not all have 'fallen on stony ground', it's been heartening to hear from some that their GP has dusted off the pack of information and used it when meeting our members in the surgery. However, it doesn't end there, a momentum has to be kept up, and without the work of our Project Co-ordinator, Ruth Smith, there would have not been such successes. We are implementing a pack of tailored information and updating all our materials.

The best part of my job is meeting our members, families and individuals, supporters and advisors, and seeing the hard work they do in fundraising, raising awareness, fighting daily battles, and determination to make lives for those living with TS better and brighter. From this, I can hear how we can target our work, and gain the essential evidence that we need to lobby, coerce and explain, to the policy makers, funders, educators, and employers. It has given me the collateral for the evaluation of essential services and materials.

The needs of those living with TS are paramount, and in particular we have won victories for people in terms of DLA, criminal justice cases, and within the school setting. This also serves to improve awareness and establish ways of working more fully in these areas. In particular, future changes to benefit systems may need scrutiny, and we would wish to be working on behalf of our community to enable them to overcome any concerns they have.

Funding and sustainability are critical in these recessive times and there are many worthy charities which are facing the same constraints as us – so partnerships are vital, as is the sharing skills and experiences. So our work with the Long Term Conditions Alliance, and such as NAS and the Neurological Alliance, has been fruitful. As such, it's been a year of careful planning, and establishing contacts that will support us in our plans.

Thank you all for those sterling efforts of those who went on fun runs, packed bags, busked for us and to all those who conducted events. The fundraising has a twofold impact, to raise monies and to let people know who we are and what we do. Our grant funders watch closely the outcomes of our work; and such team efforts do not go unnoticed: the CEO of

Children in Need explained: 'we are proud to be associated with Tourette Scotland, your reputation in Scotland goes before you, and we are pleased to support you in your aims'.

Future Work:

- Robust funding programme, and evaluation of work that will provide evidence of good value and where resources are needed
- Training, Outreach and Online Development projects: continue to extend capacity whilst seeking to sustain the work with funding support and more resources. Including our members in training and outreach, as peer supporters.
- Encourage our volunteers, advisors and staff, support them to fulfil their ambitions; and generate opportunities for them
- Adding to the interactivity/widen the range of our advisory work via networks and new methods of contact: setting up a Skype and webcam pilot, connect up bespoke networks - including outreach, online support and online training
- A media campaign, extend our awareness programme to include more bespoke and tailored materials, linked with our development of new Information Sheets, and targeted market resources. 'Soapbox' projects.
- Establish a supported programme for adults with focus on routes to employment and fulfilling ambitions, building up confidence and working with training providers, employers, social and criminal justice systems, coupled with a campaign for employment rights for TS people.
- Further the coverage areas of our national networks, including more peer groups, applied localised funding, localised events, road shows, and activities
- Use our Data Retrieval project, consult with our support teams and others, consolidate research information and give us a robust knowledge exchange both within groups, membership and practitioners
- Expand our research programme and contributing to national and international publications.



Judy Barrow, Development Manager, Tourette Scotland 29th October 2011

From our Project Co-ordinator, Ruth Smith:

Since starting to work for Tourette Scotland in 2004 I have been involved in moving offices three times. From a desk in a shared office, then to our own office above a shop, then to a nice office in a business centre (and a lovely view of Tesco car-park), and again in April this year we moved to another business centre and now have two offices, one is our main office and the other is a special support room.

Tourette Scotland
National Base



This just shows how we have progressed and got bigger (and better) over the years. The demand for Tourette Scotland is out there and we are working hard to supply what is asked for and needed, desperately; to provide advice, information and support for the 1 in 100 people who live with Tourette syndrome and its associated conditions. On a daily basis we field (by phone, email, in person) a wide range of enquiries from members, organisations and agencies; carry out research, arrange support, provide information, and are proud to represent Scotland's TS community.

We are not a Perth branch for Tourette Scotland – we are at the hub of the Scottish Tourette syndrome community, working for the whole of Scotland. Wow – isn't that something! What an achievement – and we couldn't do it without the support from you, our members, supporters, and friends. We are there for each other, and I wouldn't have it any other way.



Ruth Smith, Project Co-ordinator, Tourette Scotland, 29th October 2011

Training news from our external trainer Chris Achenbach: As External Trainer with Tourette Scotland since December 2010, my work this year has been to plan and deliver a range of training sessions in various settings, and to assist in the evaluation of these so that the charity's training programme can be further developed in future.

Education staff training sessions: Entitled "An Introduction to Tourette Syndrome", these sessions offer a summary of essential information about the nature and features of Tourette syndrome, as well as suggestions for helping children and young people with the condition, and those who support them, to overcome the challenges it poses at school and beyond. These sessions have all been delivered in schools attended by at least one pupil with Tourette syndrome. Liaison with the family concerned has been a key component in fine-tuning the session content in each case, and has been undertaken in collaboration with the charity's outreach service to children and their families.

"Tourette Syndrome" event for Highland Council, Inverness, May 24th, 2011: I helped to plan this event for Highland education staff, and was also due to present an introductory information session and chair the day. Unfortunately, high winds and rain caused travel disruption, stranding me in Edinburgh! I am happy to report that the event took place without me and evaluation feedback from participants was to a high standard. I also gave a talk to Pollock Carers' Centre (presentation focused on people of all ages with the condition). Participants' evaluation of all these sessions has been to an encouragingly high standard, providing good evidence of their effectiveness.

Peer awareness sessions: These are informal sessions for single or multiple classes in schools, designed to help pupils gain awareness of what it means for a fellow pupil to live with Tourette syndrome. While liaison with the pupil's family is of central importance in planning the content of these sessions, discussion is actively encouraged so that pupils' questions and comments can be heard and responded to. It was very encouraging to hear that, after the first of these sessions, a fellow pupil invited the child with Tourette's to have tea with them and spend the evening at their house. In the case of the second session, the pupil with Tourette's encouraged their classmates to "tic" when I entered the classroom, which sparked fruitful discussion from the outset!

I look forward to the further development of the charity's training programme during 2012.



Chris Achenbach, External Trainer, Tourette Scotland, 29th October 2011

On our pilot project for Outreach - Janice Mylan: As Outreach worker since November 2010 my job has been to make contact with families and individuals living with Tourette syndrome or suspected Tourette syndrome who need some extra support, mentoring and advice. Much of the work entails informing people about what TS is, as even after diagnosis many people have little or no information about it or how it may affect them. People have so many questions and part of my work is to source the relevant information or make referrals to relevant partner organisations or agencies, as well as within the Tourette Scotland team.

The outreach service has been conducted in a number of different ways: e mail, phone and face to face meetings in a range of settings, as the key to its success is its flexible approach, designed to offer accessible support. We use the GIRFEC model in our approach, which marries with that of review and CSP meetings.

Coping and managing certain situations/symptoms is discussed and as is sharing knowledge and experiences in order to assist and to enable people come to terms with diagnosis and to move forward. Part of the job is also about helping people through the maze of systems and services, supporting a number of parents when they are dealing with school review meetings. This has helped them to find out what their rights are, empowers them, and therefore gives them confidence. This results in their gaining the appropriate support from the school/college, and from health and social services. My work is linked with that of External Trainer, Chris Achenbach, as often schools have expressed the wish to have awareness training, after hearing about what TS is, and seeing for themselves how it affects children in school. I have had the pleasure of being in touch with many people over the months and the situations have varied, making this a very worthwhile service.



Janice Mylan, Outreach and Reviews, Tourette Scotland sessional worker, 29th October 2011

From our Website Developer, Lauren Strachan:

I first became involved with Tourette Scotland around 13 years ago when I, myself, was diagnosed with TS/OCD, and I have been Trustee for several of those years. Having run the web-site since its birth, last year I was offered the role of Web Developer. The main focus of my work has been to offer our members more avenues of support and information. We now have our online community area which enables members to communicate with each other in a private and safe space and ask questions, share stories and maybe even have a little fun along the way. Our blog was launched some months ago and offers Tourette Scotland a way of communicating what we are up to, and also invites any budding authors out there to contribute. We are about to launch a Teen Blog which will enable any of our younger members to get involved and contribute their work. We are aware there are a great many creative souls among us and so we are about to launch our online gallery where our members can share their artwork.

I am keenly aware that we now live in a world where social-networking dominates and being a big fan of Facebook myself, I understand how important it is to communicate with others on a regular basis. On a personal level, however, I feel that sites like Facebook can sometimes be a little public for some of the more complex support needs and I hope to find additional routes to ensure that everyone's needs are met. To that end, we are in the process of discussing our future plans and hope to offer more interactive communication, such as a Skype service. Tourette Scotland as a whole is something very close to my heart, having helped me with my own TS over the last 13 years and enabling me to meet some wonderful people and life-long friends.

I am thoroughly enjoying the work I am doing and I am excited about our plans for the future.



Lauren Strachan, Website Developer, Tourette Scotland, 29th October 2011

Mark Lincoln – information sharing and data Retrieval

Mark has been developing our new Data Retrieval programme this year. His Spring Meeting presentation outlined such as 'Benefits of Sharing Information'; 'Member and Volunteer needs'; 'Planning to allow us to share information'. This is not only information as an exchange between our own services to see what works well, but also between us and partner organisations and agencies. All this is to grow an understanding of TS related issues and prove, via evidence gathering, what can be done in improving lives, but also to identify new services to continue to provide the best support. This work also identifies the TS awareness levels of professionals and practitioners, and will, when complete, allow others to know where to get help from; and provide a knowledge base of 'who knows what'. This will assist in, not only our own information levels, but also serve to determine the type of support and services required in the future, provide collateral for future research, and assist with evidence for sustainable funding.

Mark will be meeting with all local groups, individuals and members of staff and volunteers, to identify areas of common needs, acting as a conduit between all our work strands. He is also our 'IT' guy, and will be helping to instigate our future Skype programmes when we will become more interactively connected.



Mark Lincoln, Data Retrieval Project, Tourette Scotland, 29th October 2011

About... our Medical Advisor

Dr Michael Morton: Dr Morton is a Consultant at the Royal Hospital for Sick children, Yorkhill. Dr Morton's personal interest in the mind/brain interaction has been facilitated by close working with colleagues in Developmental Paediatrics and Neurosciences. He is leading a research project into creating Pathways within services, for those with TS, with Tourette Scotland adding evidence and sharing presentations.

He has been assisted in his work to promote further services for people with TS, by **Martin Donnelly:** Nurse Therapist, also at Yorkhill. He has been instrumental in supporting us in our aims, conducting surveys, as well being supportive of our work in his day to day professional role. Martin has recently trained in Habit Reversal Therapy.

Report from Trustee Treasurer, Tony Lambert: I am pleased to report another productive year and we go forward, as ever, with the best use of funds remaining at the forefront of the Trustees financial decision making. A retired accountant, I have been the Finance Officer for Tourette Scotland since mid 2004, as a volunteer and Trustee Treasurer. I am proud to be a part of the organisation and the good work it does. My role entails not only having to chase up receipts and paperwork, but also to write out the much awaited cheques!

As well as JustGiving.com we also enrolled in the Virgin-Money direct giving system, so that we can access more local and national fundraising events. These systems, along with our web-based WorkwithUs, have proved to be successful methods for collecting donations or sponsorship. Any of the groups organising their own fund-raising can set up a link to Tourette Scotland's website, for a particular event with details and a photograph. Gift Aided donations are added to the overall sum. Collecting boxes have been distributed and are allocated via our Project Co-ordinator, with the proceeds going directly to group funds. All the groups have a cash box in which to keep their cash floats secure, and co-ordinators keep accounts that are included our audit. This year, some accounts were also audited from the bank statements and may I say thank you to support co-ordinators for their great efforts.



Tony Lambert, Trustee Treasurer, Tourette Scotland, 29th October 2011

Support Group Highlights



Spotlight on: The Highland Group of Tourette Scotland

The Highland Group of Tourette Scotland currently has a mixture of children and adults who meet monthly in the Inverness area. In the winter they gather at the Roller Bowl where it is so noisy and busy that no one notices any unusual behaviour, and during the summer months they enjoy visits to Landmark and the Black Isle Wild Life Park. The children have a great time playing with each other while the parents have a chat over coffee. Having had an adults meeting where they went out for a Pub meal, they are planning more. They advertise themselves as widely as possible and a contact card is given out by schools in Ross-shire to all newly diagnosed children. They also have a poster up in the Inverness Children's Services building where Child Psychiatry and Psychology are based, and have developed a good set of contacts within the services. As such, they hosted a well-received TS training session for 60 professionals in May, where the testimonies of their younger members had a hard hitting message for the practitioners, about how TS impacts on lives and what was needed in terms of services.



Fife Support Group: As well as monthly Support Group meetings, the Fife Support Group held 'Road shows' throughout the area, as a way of informing others about TS and inviting them to meet the Group members. These events attracted new members and visitors including educationists and medical practitioners. The group hosted activities including a family weekend at Ratho, and their now famous water sports day and BBQ at Lochore.

West of Scotland Support Group: Their meetings are held in the Pearce Institute, Govan, which has proved to be a great venue: the meeting room boasts a café, is big enough to include arts and crafts for the children at one end of the

room, whilst adults and invited speakers can get together at the other end. It is working as well in bringing together the growing membership in West.

The Borders Support Group: Due to its location, this group attracts TS friends from 'over the Border' too, and they put on a big event in April this year, based at the Langlee Centre, Galashiels, which was well supported by several families and adults with TS, who enjoyed a great day of activities and the opportunity of meeting one another.

We welcome the newly formed East of Scotland Support Group which is now regularly meeting in and around the Stonehaven area, and already have a thriving attendance at their lively meetings. Putting on a range of activities, include cartoon making using a computer and plasticine figures (watch out, Aardman), and making personal scrap books about their TS. The group is already drawing together families and adults with TS in this corner of Scotland.



The Central Scotland Group will be hosting its inaugural meeting at the end of November 2011, and will serve the Perth, Stirling and Falkirk areas.

GRATEFUL THANKS

Grateful thanks to our Fundraisers, Funders, Trustees, Volunteers and Supporters.

Thanks to our Fundraisers: all those who gave their time to fundraise, make donations, gave raffle prizes and hold local events for us during this year

Especially: Reagin and the Buskers, Ingrid Abualrous, Debbie Cadden, Judy Barrow, Dave Thomson, the Fife Bag Packers, the Fife Abseilers



NATIONAL OFFICE:

Project Co-ordinator: Ruth Smith
Development Manager: Judy Barrow

National STAFF AND VOLUNTEERS:

Line Management: Olav Skretterberg
External Training: Chris Achenbach
Data Retrieval: Mark Lincoln

ADVISORS:

Legal Advisors: John Fotheringham, Steve Kelly
Medical Advisor: Dr Michael Morton
ADHD Advisor: Bill Brown

Outreach Officer: Janice Mylan

Web Master: Lauren Strachan

Special Projects: Andrew Taylor

Support Group Co-ordinators: Michelle Ross, Susan Peebles, Barbara McGrouther, Pauline Hamilton, Lesley Fletcher, Clare Dyker, Jocelyn Caveney, Dot Achenbach, Kerrey Mitchell, Paula Miller, Kathleen Forbes

Finance Officer: Tony Lambert

Counsellor Support: Angela Lamont

COMMITTEE of Trustees:

Chair: Olav Skretteberg

Vice Chair: Louise Lowdon

Treasurer: Tony Lambert

Secretary: (acting: Judy Barrow)

Jocelyn Caveney, Mark Lincoln, Lauren Strachan, Susan Peebles,

Suzanne Easdon (nominee), Steve Kelly (nominee)

Thanks to our grant makers: Children in Need, Lloyds TSB, Robertson Trust, Souter Trust, Gannochy Trust, Stafford Trust, Workload



WorkLoad

