

contact a family

for families with disabled children



**30 years of
strengthening
families with
disabled children**

Anniversary Special July 2009

Wandsworth Contact a Family 1 Seward Road SW17 0LA. Tel: (020) 8947 5260

**Wandsworth.office@cafamily.org.uk Charity No: 284912
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Seagull Print London 020 8944 7366

Happy Anniversary to us!

30 years on and Contact a Family still continues to support families with children who have special needs. In Wandsworth alone, we have 600 families on our database at any one time – many of whom stay with us from the time they realise their child has special needs up to when they are 19 years old and move on into adult services.

When Contact a Family was established in 1979, the world was a different place – the Internet and mobile phone technology was a thing of the future – so families who needed help and advice relied entirely on meeting professionals face to face to get information. As now, there was limited time for this, so parents started to meet up and discuss their issues to come up with suggestions for one another. We have some video footage from 1981 of parents talking about how much they rely on support from each other and from Contact a Family to help them through the more challenging aspects of bringing up a disabled child, particularly in the early days.

More recently, parents choose other ways to get in touch – through their mobile phones or our Facebook page or makingcontact.org but there are still always those parents who prefer to meet up face to face. For this reason we are running a whole series of groups across the borough over the summer, where parents can bring children to take part in Fun sessions.

We also have a great opportunity for some of our older children to go to the local theatre in Wimbledon to see High School Musical 2 – we are looking to do more of these theatre trips in the future as they are always oversubscribed and people really enjoy them.

Good wishes from the whole team to everyone hoping you have a good summer holiday and are able to access support if you need it. Our office is open throughout the summer holiday but there are many events going on so it is still important that you call to make an appointment if you would like to see someone.

Rosie Noble, Manager 020 8947 5260



Roehampton and Putney - News from Claire

Roehampton Play and Development (Tuesday Group)

Roehampton and Putney Play and Development group for young children with special needs and disabilities will be closing over the summer break. The first session in the autumn term will be on

Tuesday 8th September 2009 at the usual time 12.15 - 2pm.

If you would like to know more about joining the group in September please call me on **020 8789 0012**

Summer Break

In addition to the borough wide events Contact a Family is running this summer, there are two local events for families of young children with special needs and disabilities in Roehampton and Putney that will be advertised in the forthcoming newsletter.

Wednesday 19th August 2009
Roehampton and Putney Picnic
Richmond Park

(Weather permitting)

We will take face paints and the parachute for some games!

Meet at Sure Start reception at 11.30 with a picnic

Tuesday 25th August 2009

Play session

Open to families with disabled children and their siblings

Toy Library play space, Sure Start Roehampton

(Siblings welcome, for children five and under)

12.15-2pm

If you would like to book a place at the play session or picnic please contact me on **020 8789 0012** to book your place.

Sure Start Summer Programme

In addition I will be helping out at the following **Sure Start** activities, if you are a member of Sure Start Roehampton these can be booked **separately** through the Sure Start team. Please call **020 8789 0572** to book and find out more about the full programme for children 5 and under.

Tuesday 11th August 2009 Sure Start Teddy Bear's Picnic
Meet at Sure Start reception at 11.30am with a picnic to take up to Wimbledon Common

Friday 14th August 2009 Crafts session
A variety of crafts activities for children up to the age of 5 years and siblings up to the age of 8 years. 50p per child (booking required at Sure Start reception, 166 Roehampton Lane)

Monday 24th August 2009 Buggy walk to Vine Park in Barnes
Meet at Sure Start reception at 10am

If you or your children have any particular requirements to make these activities accessible and enjoyable please let the Sure Staff or me know prior to the date.

I hope you and your family have an enjoyable summer break.

Claire Hayes

020 8789 0012

claire.hayes@cafamilly.org.uk



Tooting Locality Information: Jill and Roxanne

We have continued to run groups from Balham Nursery, following requests from parents we have invited along guest speakers.

A member of the community Dental Team came along and gave a talk on oral hygiene. The feedback was that the parents found the information and the handouts useful; they were stunned at the levels of hidden sugars in everyday foods! Parents would have benefited from the advice being more specific to their individual children's needs.

All children with disabilities who are unable to attend a regular dental practice are able to access specialist services run by the community dental team. There is a referral form, which family workers can complete on your behalf. We also have copies of the catalogue, which sells specialist toothbrushes and other dental equipment. Please contact us if you are interested in finding out more about the services on offer.

Following request from parents we have planned a number of fun mornings to be held throughout the summer holidays. All families with a child under the age of 5 years are welcome. Please contact us for more information on **07508 734 333**.

We will continue to run groups from Balham Nursery after the summer holidays. The dates will be confirmed in the next newsletter.
Wishing everyone a happy summer,

Jill and Roxanne
07508 734 333



Battersea Early Years' Team - News from Suzanne

Just a quick reminder to everyone that I am now based at Chesterton Centre for Children and Families and would be very happy to hear from anyone who lives in the Battersea locality who has a child under the age of 5 and would like support from me on anything relating to your child's special needs, such as with benefits, accessing funds, meeting other families in the area etc. I can advise you on the phone, arrange to meet you at one of our centres or visit you at your home.

I have received a very warm welcome from all the families I have met so far and have been very happy to introduce some new members to Contact a Family. It has been really nice meeting you all and I look forward to meeting many more families over the coming months. Thank you to those who have sent in your feedback on plans for setting up a regular parent group for families in Battersea who have at least one child in their family under the age of 5. I hope to be setting up a regular group in the new autumn term, so watch this space!

I look forward to seeing many of you at our summer activities!

Suzanne
Chesterton Children's Centre
Battersea Early Years' Team
020 7622 1619 ext 112



**ADDITIONAL SUMMER EVENTS.
COMPLETE AND RETURN THE BOOKING FORM ENCLOSED**

| Event | Date | Time | Venue | Venue address |
|----------------------|---|----------------------|--------------------------------------|---|
| Fun Morning | Mon 27 th July 0-8yrs | 10.00am - 12.00pm | Somerset Children's Centre | 157-159 Battersea SW11 3ND |
| Fun Morning | Tues 28 th July 0-8yrs | 10.00am - 12.00pm | Faylands Children's Centre | Faylands's Avenue SW16 1TB |
| Fun Morning | Fri 31 st July 0-8yrs | 10.00am - 12.00pm | Early Years Centre | 1 Siward Road, SW17 0LA |
| BIG DAY OUT | Wed 05 th Aug All ages | 12.00pm - 3.30pm | Leave Early Years' Centre at 10.30am | Hyde Park |
| Fun Morning | Thurs 6 th Aug 0-8yrs | 10.00am - 12.00pm | Early Years Centre | 1 Siward Road, SW17 0LA |
| Fun Morning | Mon 17 th Aug 0-8yrs | 10.00am - 12.00pm | Somerset Children's Centre | 157-159 Battersea Church Road SW11 3ND |
| High School Musical- | Thurs 20 th Aug over 11's | 7pm | New Wimbledon Theatre | OVER 12'S ONLY |
| Fun morning | Wed 26 th Aug 0-8yrs | 10.00am- 12.00pm | Chesterton School | Dagnall Street, SW11 5DT |

High School Musical tickets will cost £12 each – make your own way.

Costs for the fun morning are £1 per child. – make your own way. Please note parents are responsible for their children at all times on the outings and activities. Please remember to abide by our code of conduct which will be given out on the day. **NB:** These events have been arranged in addition to the Bocketts Farm and Brighton events which prioritised children aged 8-13. To apply for a place, fill out the Booking form enclosed with the newsletter and send it to us at **1 Siward Road London SW17 0LA or email to us.**

Summer Saturdays Great Big Family Arts Project



We would like families and children 0-19 to join us in a family arts project to design and paint a mural on the exterior walls of the Early Years Centre outdoor play area.
The dates for the project are as follows:

Saturday 25 July 10.30-2.30
Saturday 1 August 10.30-2.30
Saturday 8 August 10.30-2.30

Join us if you fancy getting creative with your children this summer, celebrating Contact a Family's 30th anniversary and making a piece of artwork which will be enjoyed by all children and families using the Early Years Centre.

No experience in drawing or painting necessary!

Places are limited to 12 families per session.

We encourage you to book one, two or all three sessions.

Please remember to wear old clothes/overalls, we could be messy!!
Call 020 947 5260 to book your place as soon as you can, as we anticipate a big response to this exciting venture



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Autism News

Many thanks to all of the parents who came along to our workshops this term, both of which were led by the Garratt Park Advisory Team. It was great to see you all, and to get your feedback on the sessions. Our 'making social stories' workshop focussed on developing children's social understanding. Hopefully the session gave everyone more of an idea about what social stories are and how to tailor them to your own child's experiences. A big 'thank you' to Julian and Louise for leading the session.

We also had a session in the IT suite at Garratt Park School, using the program 'communicate in print 2'. We had a really productive session and everyone had fun making visual aids for their children. Some went away with a visual timetable for their child; others made key rings with different flash cards to help with their child's understanding. Many thanks to Paulette for the help, advice and resources!

We shall be organising another set of workshops for the autumn term and information on these will be in the next newsletter.

We continue to have a monthly support group, here at the Early Years Centre. Jo Brooks, head of the Advisory service, has been attending the final hour of recent sessions, offering advice on various issues such as behaviour, social skills and school-related questions. Next term's support group dates will be in the next newsletter.



Note about Autism:

We are aware of various initiatives around working with children with Autistic Spectrum Disorders and are increasingly asked our opinion of them.

We are not able to pass any judgement on possible treatments or therapies. We would always refer parents and professionals to the National Autistic Society: www.nas.org.uk/nas/jsp/polopoly.jsp?d=297 to look at their opinion on the different strategies surrounding autism.

We feel that parents know what is best for their child and would urge you to look up and research any 'new' idea to ensure you feel it is a good option for your child. No two children are the same and what works for one may not work for all. If you would like to speak with us further, do call us on the usual number.

ADHD news

Thanks to everyone who has been attending the recent workshops and groups, based around ADHD. The presentation from Melissa Hood, focussing on raising children's self-esteem, gave most people a very positive set of strategies to use with their children. Unfortunately we were unable to go ahead with the talk from Sue Norgate, head of special needs assessment. We are aware that many of you were disappointed by this and will endeavour to re-book Sue when it becomes possible.

We have also conducted a survey of parents of children with ADHD, to find out what difficulties they face and what support they would like from groups and workshops. It has been great to get your feedback and, as a result, we intend to organise the groups with more structure in the future. If anyone has any more suggestions for topics or speakers, then please contact Claire Cox. The next dates and further information on groups and workshops will be in the next newsletter, after the holidays.

News News News

Attitudes Towards Disability Shocking Say UK Families with Disabled Children

Families with disabled children in the UK feel stigmatised and shut out from society, according to new research published by Contact a Family. Contact a Family surveyed 615 families with disabled children about their experiences of living in the UK, asking what makes you stronger practically, socially and emotionally.

'What makes my family stronger' found negative attitudes towards disability coupled with a lack of services are the main barriers preventing families with disabled children from leading ordinary lives. While some families show resilience, imagination and great strength attempting to overcome these barriers, there are some who cannot cope any longer and are at breaking point.

Srabani Sen, Chief Executive of Contact a Family, said: 'It is shocking that in the UK today, attitudes towards disabled children, from professionals and members of the public are among the barriers preventing families from leading ordinary lives. Families with disabled children have enough challenges to overcome to secure the support they need without also having to cope with prejudice and ignorance.'

Contact a Family is calling for:

- The government to invest in a UK-wide campaign to raise awareness of the needs of families with disabled children.
- Everyone working in a public facing role in the UK to be given disability equality training. And stronger focus on disability awareness in schools.
- The much welcomed and significant investment in short breaks services in England must be sustained and included in the next Spending Review.
- The government to commit to urgently reviewing carers benefits and set a clear timetable for reform.

Read the report in full at Web: www.cafamily.org.uk/wmmfs.pdf

Contact a Family premieres new films

Contact a Family is premiering three new short films about families with disabled children. The web videos feature families talking about their experiences of raising a child with a disability and the best sources of support they have found. You can view the films on our YouTube channel at Web: www.youtube.com/user/cafamily .

New Ways to get in Touch on MakingContact.Org

Contact a Family's flagship social networking site now has message boards to enable families with children with rare conditions across the world to share experiences and support each other. There are over 6,000 parents registered on our on-line service MakingContact.org. Parents can make contact with others whose children have the same condition in order to gain, and give, support through the sharing of experiences and knowledge. For more information visit Web: www.makingcontact.org .

Simpler Rules on Backdating Extra Tax Credit Payments

If your child is awarded Disability Living Allowance (DLA) or has an existing DLA award increased to the highest rate, this can lead to extra child tax credit payments, known as the disability elements.

Prior to April 2009, any parent who wanted to make sure these disability elements were fully backdated had to notify tax credits both when they claimed DLA and when they got a DLA award. Many parents lost out because they were unaware of the need to tell tax credits that a claim was being made. However, since April 2009 the rules have been simplified. Now you only need to notify DLA once - when you get an award. If you are awarded DLA for your child (or have an existing award increased to the high rate for personal care) let tax credits know within three months of the DLA decision. So long as you do this, any extra tax credit payments will be backdated in line with the DLA award.

You can access the new rules in full at Web:

www.opsi.gov.uk/si/si2009/pdf/uksi_20090697_en.pdf

If you have any questions about this or any other benefits issues please contact our helpline on Tel: 0808 808 3555.

Parents of Disabled Children Delivery of the 'Core Offer'

The Office of National Statistics has published an overall satisfaction score of parents of disabled children of 59 out of 100 for delivery of the government's 'core offer' for disabled children. The 'core offer', introduced through Aiming High for Disabled Children, is the commitment from local authorities and Primary Care Trusts to disabled children and their parents on how they will be informed and involved as their needs are assessed and necessary services are delivered.

Aiming High for Disabled Children also introduced a new national indicator - NI 54 - on services for disabled children. NI 54 assesses parents' general experience of services for disabled children aged 0 to 19 and the extent to which services are delivered according to the 'core offer'.

To download the DCSF Statistical Release visit Web:
www.dcsf.gov.uk/rsgateway/DB/STR/d000846/index.shtml

New National Representative Body for Special Schools

The Department for Education and Skills has provided £150,000 in start-up funds to create a national representative body for special schools.

The new body is called the 'Federation of Leaders in Special Education' (FLSE). It aims 'to shape and deliver SEN policy to ensure every child's needs are met'. They welcome all those who are involved in the education of children and young people with special educational needs.

For more information visit Web: www.flse.org.uk

Parents of Disabled Children Included in Plans for New Savings Scheme

The government has included families with disabled children in their plans for a savings scheme called the 'Saving Gateway'.

From 2010 the savings scheme will be open to people of working age on low incomes and in receipt of specified benefits, including Carer's Allowance. For every pound saved the government will give a contribution of 50p. Savers will be able to pay up to £25 a month into their account for two years, which means a potential contribution from the government of £300 after the two year period.

For more information visit Web:

www.direct.gov.uk/en/MoneyTaxAndBenefits/ManagingMoney/SavingsAndInvestments/DG_10010450

Online Advice About Equipment for Disabled Children

Disability charity, the Disabled Living Foundation has launched an advice and information website on equipment for children and young people with disabilities.

The site, Living Made Easy for Children has been created by an occupational therapists and aims to bring together information on every product for children and young people with disabilities into one place.

For more information visit Web: www.livingmadeeasy.org.uk/children

New Website for Young People with Mental Health Problems

YoungMinds have launched a new website 'My head Hurts', a new website for young people with mental health problems. It provides information to young people diagnosed with anxiety, self harm, conduct disorder, depression, ADHD and eating disorders. The idea for the site came from young people themselves and they have been central in its creation and content.

For more information visit Web: www.youngminds.org.uk/my-head-hurts .

New Sign Language Advice Films

Community Legal Advice (CLA) has created a set of films that give advice in British Sign Language (BSL) to people who have large debts, have been made redundant or are at risk of losing their home. The advice is in BSL, but a voiceover has been added. Titles include: dealing with debt, losing your home, dealing with rent problems - if you rent privately, claiming benefits, problems with schools and care proceedings.

Watch these films on YouTube :

www.youtube.com/user/communitylegaladvice?gl=GB&hl=en-GB .

Giving Children and Young People a Right to Appeal Statements of Special Educational Needs

The government are currently running a consultation on giving children and young people a right to appeal decisions on exclusions, SEN statements and assessments, and to make disability discrimination claims in England.

They are seeking the views of children and young people, parents, carers, governing bodies, local government, school staff, teaching and support staff unions (including professional bodies), tribunal and independent appeal panel members, associated representative organisations and the voluntary sector.

The consultation ends on Tuesday 28th July 2009.

Take part in the consultation at:

<http://www.dcsf.gov.uk/consultations/index.cfm?action=consultationDetails&consultationId=1607&external=no&menu=1>

Volunteers needed to Help Research for Genetic Counsellors

The Medical Research Council, in collaboration with The Genetic Interest Group, is carrying out research to develop new ways of measuring how people with genetic diseases or conditions might benefit from seeing a geneticist/genetic counsellor or attending a genetics clinic (a place where people can be tested, diagnosed and counselling can be offered to help cope with the affects of a diagnosis).

They are looking for people aged 17 years and older from families affected by genetic conditions to help with this, by completing an early version of their questionnaire. You do not need to have used a clinical genetics service yourself to help with this research. There has been very little research in this area and this is an opportunity for you to help with research that may improve services for affected families.

Use PIN number 1144 to access the questionnaire, fill in the consent agreement and then complete the questionnaire. You can withdraw from it at any point. To complete the questionnaire online go to Web: www.geneticsforpatients.org.uk/ .

For a paper copy of the questionnaire please contact: Marion McAllister PhD, MRC Research Fellow, Tel: 0161 276 8979

Nightingale Walk



Once again we manned a stall for the Nightingale Walkers who continue to raise money for us each year. We saw them all at the Ham House stop on Saturday 23rd May 2009. Ati and Rosie had a lovely day greeting all the walkers and providing refreshments for their 21 mile walk! It was especially exciting as it was also the 30th anniversary for the Nightingale Walk and everyone was in a great party mood.

'It was thirty years ago today we showed you how to walk this way'

The walkers have raised over £420,000 for various charities over the years - what an achievement!

Carer Participation and Volunteer Development Officer

Hello to all Carers in Wandsworth,

My name is Daniel Blagdon and I have recently joined the team at Wandsworth Carers Centre as the **Carer Participation and Volunteer Development Officer**.

As a carer you have a wealth of experience and knowledge about the services that are available across the borough. Because of this you are in the perfect position to utilise your insights into how local services can improve what they do.

I am here to work with and for all Carers across Wandsworth, to make sure that Carers have an active role in developing local services and can contribute to issues which are important. Together we can hopefully make a difference to the lives and experiences of Carers across the borough.

In addition to this I will be working to expand and develop the existing volunteer services provided through WCC, which currently include counselling, complementary therapies and support services.

Before joining Wandsworth Carers Centre I have worked in Wandsworth for over 6 years on a variety of community and engagement projects. Most recently I worked for Wandsworth Primary Care Trust on an 'Engagement' project enabling local people to get involved in shaping services they provide.

You can get in touch with me at the Balham office, Mon - Fri using;

Phone: 020 8675 0811

E-mail: daniel@wandsworthcarers.org.uk

Post: 46 Balham High Road, London SW12 9AQ

I am really looking forward to meeting and hearing from as many of you as possible over the coming weeks and months as we work to move things forward together.

Daniel

contact a family

for families with disabled children

Across the UK, a child is diagnosed with a severe disability every 25 minutes. Although some children need hospital care, 98% of disabled children live at home with a parent or other family member who may not have expected to be in this position but who has quickly had to become an expert.

When parents find out that their child is disabled they feel isolated and alone, because usually they don't know anyone else facing the same problems. They want contact with another family who've been through a similar experience and they want information about their child's disability.

Contact a Family is the **only** UK-wide charity providing advice, information and support to the parents of all disabled children - no matter what their disability or health condition. We also enable parents to get in contact with other families, both on a local and national basis. Each year we reach at least 275,000 families.

The Contact a Family National Helpline

Freephone 0808 808 3555

10.00 – 16.00 Monday to Friday and 5:30 – 7:30 Monday

- Give you **information on medical conditions and disabilities** affecting children, including very rare disorders. All the information is written by leading experts in the field, specifically for parents and families
- Advise you about help which may be available, including **special educational needs assessments**, getting help to have a **holiday**, your rights to **benefits and tax credits**, and **services** for families with disabled children. We have a wide range of **free [fact sheets](#)** on these issues which you can obtain from the helpline.
- Put you in touch with **UK-wide and local support groups**. Many families like to share experiences with others caring for a disabled child and find the support this can bring invaluable. If your child has a rare disorder and there isn't a group we might be able to **link you with another family** on a one-to-one basis.
- Tell you about any other specialist **voluntary organisations** which may be able to help.
- **Listen** - many parents simply wish to 'tell their story'

Aiming High update

Parent Participation

The Parent Council has continued to meet on a regular basis and has now formed into 'Positive Parent Action' – a group of parents of disabled children across the borough who will be reaching out to as many parents as possible to get views on what is happening to feed back to Wandsworth Children's Services and NHS Wandsworth (formerly known as the PCT). The group has been successful in obtaining the phase 2 part of the funding so will be able to really get started now – look out for newsletters and other updates very soon.

Already three parents were part of an interviewing panel for the Aiming High Implementation and Commissioning post and the short breaks consultant has been to one of their meetings to get their views on the proposals for the new short break schemes next year.

For more information you can contact them on:
positive parentaction@yahoo.co.uk

Short Breaks

Interviews have taken place for the Implementation officer post and at the time of going to press we are still waiting to hear of the outcome – we will keep you informed.

Transition

Work has been going on around what happens as our young people head off into the adult world and now a group of professionals will be meeting this summer to look at ways to improve the transition process in Wandsworth – we will keep you informed



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**Contact a Family's 30th anniversary celebration
in Hyde Park on Wednesday 5th August**

We will meet up with families from our other projects across London. Families will bring a picnic to the venue where there will be some entertainers and children's activities. A coach will leave the Early Years' Centre at 10.30am and will leave Hyde Park at 3.30pm

Places are limited for this event as we are able to take **one coach only** so please send in your **request form** by Friday 24th July so we can allocate the places and let the lucky families know. There will be a refundable £5 deposit for families awarded a place.

We know this event will be popular so please understand we will be drawing names out of a hat to decide on who can attend. We are sorry not to be able to take everyone but it is out of our hands.

*Wandsworth Contact a Family
1 Siward Road
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SW17 0LA*

020 8947 5260

wandsworth.office@cafamil.org.uk