

EVERYONE MATTERS

FORCES ADDITIONAL NEEDS & DISABILITY FORUM (FANDF) NEWSLETTER



SERVICE CHARITY SUPPORT WITH WESLEY UPTON

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WELCOME

Welcome to another New Year and another FANDF (electronic) Newsletter. I hope you all had an enjoyable Christmas and that 2016 will be a happy and positive year.

Our long-standing Newsletter Editor, Heather Smith, has handed over the reins to Jo Hoskin. I would like to thank Heather for her numerous years of hard work and commitment as Newsletter Editor, on behalf of FANDF past and present and wish Jo good luck with her new role. Jo will introduce herself in this edition, along with some of our other new Committee members. We always welcome articles for the Newsletter, so it would be wonderful to receive your news articles, any tips or information you have found useful which may help other members - or anything you would be happy to share with our readers.

We are looking forward to the FANDF Conference at the MoD in June, which will follow the same format as previous conferences, and look forward to seeing many of you there.

I hope you enjoy reading the first Newsletter of 2016!

Best wishes

Iza Gill
FANDF Chair



FANDF COMMITTEE MEMBER AND NEWSLETTER EDITOR JO HOSKIN



I joined the FANDF in November 2013 after my son, James was diagnosed with ADHD and Asperger Syndrome. He was 8 at that time and we had struggled for years to get a diagnosis and any sort of support. Once CAMHS had confirmed what we had already known, I was on a mission to access any support network that I could find! I myself have Fibromyalgia and other health issues, so was grateful that FANDF could cater for both of our needs.

Back in the autumn I was tasked with the role of compiling the FANDF newsletter after Heather Smith stepped down from the committee after 25 years of service. I would like to express my personal thanks to Heather for giving me such a comprehensive handover and I do feel I have some very big shoes to fill! So to assist me in this mammoth task, I would be grateful to receive anything that you would like to contribute to the newsletter be that an article you have read, any training or conferences you have attended, or even a lovely drawing by your child! This is YOUR newsletter and I will do my very best to make it interesting, relevant and informative for you all.

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Any articles or items of interest can be sent to:

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SSAFA Queen Elizabeth House, 4 St Dunstan's Hill,
London EC3R 8AD

Email: Frances.r@ssafa.org.uk

*Please Note: The Newsletter can be photo copied and passed on. Views printed in this newsletter are NOT necessarily those of the Editor or SSAFA.

FORCES ADDITIONAL NEEDS & DISABILITY FORUM CONFERENCE

MONDAY 20 JUNE 2016 - MoD MAIN BUILDING, LONDON

We would be delighted if you can attend our FANDF Biennial Conference this summer. Following the success of our 2015 Spring Event we have invited guest speaker Geoff Evans, Independent Autism Trainer and Consultant, to speak again. He will give an interactive discussion on additional needs and disabilities which will include positive behaviour management topics. There will also be an opportunity to ask questions to a panel of relevant tri-Service and welfare professionals. Representatives from the MOD, other charities and organisations will be at this event and this is a great time to network and ask any questions.

We invite you to the pre-Conference dinner on 19th June, which includes overnight accommodation in London at the Union Jack Club. All travel costs will be covered too.

If you require further information about the conference do not hesitate to contact Frances Robinson the Short Breaks Leader and AN&D Adviser on **020 7463 9315** or Email: Frances.r@ssafa.org.uk

Application deadline is for 27th April 2016.



NEW FANDF COMMITTEE MEMBERS



ROBERT HALL

As a parent of a child with additional needs I know the difficulties which a family can be put under dealing with the many challenges it brings. Since finding out about the FANDF I have attended many

of the planned events which have helped me face these challenges. It has also given me the confidence to speak out about my own personal experiences in the hope that I may be able to help others. This is one of the contributing factors as to why I joined the FANDF committee.

During my 5 year tour in Cyprus my wife and I started a family and were blessed with 2 boys. Over the coming years my youngest son started showing difficulties. At first we just thought he was a child with challenging behaviour. This behaviour over time started to affect the way we functioned as a family.

We moved back to the UK in 2011. During this 3 year tour I spent 14 months away in NI. My wife was unfortunately left to handle my son's behaviour alone. It was also the time that my eldest son moved to boarding school, a decision which we thought long and hard over and one which we do not regret. With my eldest away my wife focused on getting our youngest the help he needed. Through grit and determination my wife gathered all the professionals around one table under a TAC (Team Around the Child). This focus group discussed everything about our son and initiated a SEN (Statement of Educational Need). At last we were getting our child the help he needed educationally.

On my return I submitted a move to a static posting within Lincolnshire. With the SEN in place and the TAC moving with him we started the process of dealing with his behaviour and social difficulty. Through many visits to a paediatrician my son was diagnosed with High Functioning Autism. Although we were expecting this outcome nothing really prepares you for seeing it written down. Over the small amount of time since his diagnosis I have researched everything I can about it.

Over the months which followed I found out about the FANDF and the help they give to Serving families. I

have attended 2 conferences to date and with each one I have come away with useful information to assist my son. In addition to my sons diagnosis I also have a close family member who suffers from acute mental health issues. This in itself has its own difficulties, given the support and guidance that the FANDF offer I am more than confident that I will be able to meet the challenges associated with this debilitating illness.

My decision to join the FANDF as a committee member was taken as I felt my experiences with both my sons High Functioning Autism and my family members Mental Health issues gives me a real insight into the struggles that Serving families deal with on a day to day basis. My hope is that I can alleviate some of the concerns people have with dealing with disabilities within the Forces and hopefully guide people through their difficult times. The main message I want to get across whilst being a FANDF committee member is just to say that you are not alone and that people are always there to help.



WESLEY UPTON

Hi FANDF members my name is Wesley Upton, I am a serving member of the Royal Navy and recently joined the FANDF Committee. I am married to Joanne and have two sons Zachery (4) and Finlay (2).

Zachery is a 5 year old neuro typical child that loves Lego, Hot Wheels and running around playing sport, he is a wonderful, kind and caring brother to Finlay.

Finlay is now 2 years old and was diagnosed at 4 months old with a rare form of complex epilepsy called West's Syndrome, we have tried various medications and have undergone various tests. We do not have or have ever had good seizure control and have gone through the Childhood Epilepsy Surgery Service program to try and find a focal point, without success, to allow brain surgery. Finn has severe learning difficulties and is autistic. We have recently started the Ketogenic diet and are very happy with the effects it has had on his epilepsy so far. We are

currently fighting to ensure that Finn gets into a suitable Special Needs nursery that will be able to provide the appropriate level of care for him.

As all Forum members will attest to, we have quickly learned that life with a child with special needs child massively alters every aspect of our lives and getting the support that you need is a minefield!

This coupled with military life can make life extremely difficult and that is why I have joined the FANDF committee, to help to make life better for those parents, spouses and children with Additional needs or disabilities.



ALISON AND ALAN BOWIE

As a doctor in the Royal Navy, Alan has worked closely with various Welfare agencies for a number of years. Neither of us thought that we would need the help of SSAFA before our son

Tommy was diagnosed with autism aged four. Since then Alison has balanced her work as a crafter and her responsibilities as a mother of two alongside volunteering with a number of charities, including training as a Face2Face Befriender. Alan has been keen to promote the work of SSAFA and the FANDF to his patients, helping families in our position to find the help that they need.



NAOMI SIZE

My name is Naomi my husband is in the army and we have four children. The eldest of our children has a rare chromosome disorder, a duplication of 22Q11.21. It does not have a name, just lots of numbers! She

is 16 and we have spent the whole of her life following my husband around on postings with the army. This has greatly added to the confusion around her diagnosis and treatment.

I have felt isolated and frustrated many times over the years. The feeling of getting somewhere and then being posted and having to start all over again is very

familiar. I joined FANDF as I thought it would be way to support other families who may be experiencing the similar problems. I believe that service families with a member with additional needs sometimes face extra pressures on top of those associated with supporting a serving family member. Being a member of FANDF gives me the opportunity to help support other families by getting these issues listened to.



HELEN MERRICK

My partner & I have spent 15 years within the service community and I would say I have gained considerable knowledge within that time.

I have significant experience within the field of special educational needs (SEN), I have managed to influence policy makers into bringing in a Safeguarding clause into the Continuity of Education Allowance (CEA) as prior to 2013 there was none. I have educated Units and Brigades on JSP 820 & AGAI 108. I have also worked for AFF for two years until our move out of the area. I have used a lot of the services on offer for service families and challenged the poor practice and received better service as a result. I currently volunteer within our local Primary School and also provide cover when needed as a Teaching Assistant for the SEN cohort. I have found this invaluable and very rewarding personally.

I have just started my own support group for families within our area to help with the isolation out there for families with children with additional needs. It is not an Autism Group; it is all encompassing so as not to exclude any one child/family. I have all the local support groups on board as well as the local SENCo's and the UWO. I have done this to share my wealth of experience with others just starting on their journey so they are empowered with the correct information and tools to get the best for their child/children and to show they aren't alone, there are others who understand and more importantly can relate.

As a committee member I'm looking forward to attending my first FANDF Conference this year and hopefully see you there!



SERVICE CHARITY SUPPORT – WESLEY UPTON

Wesley Upton, FANDF committee member, shares his experience of the support that he and his family were given from The Royal Navy & Royal Marines Children's Fund.

In August 2013 we were away at Hendra Campsite in Newquay camping for the Bank Holiday Weekend with friends, Finn was 4 months old and we had no concerns about his health or well being, he was developing as would be expected. During the weekend we noticed he started to make some strange movements which looked to us to be like colic. We monitored him and decided to take him to the doctor on our return if he did not get better. We took him to our local surgery and the doctor said she was not too worried but would book him and appointment with paediatrics at Truro hospital. We got increasingly concerned about the movements as the frequency increased massively and my wife sent an email with attached video to the paediatrics department that night and by 08:00am the Paediatric department called and told us to take Finn into hospital immediately after two days of tests he was diagnosed with Infantile Spasms/West Syndrome. We were shocked and terrified about what the diagnosis would mean for Finn and our whole family.

We were sign posted to RNRM welfare that were and have been fantastic thorough out our dealings with them. We were a family in crisis and with the relentless routine hospital appointments we were struggling to cope with looking after our oldest son Zac and our friends were amazing and looked after him for days at a time. Our RNRM welfare worker sign posted us to the The Royal Navy & Royal Marines Children's Fund to help with child care they provided funding to put Zac into nursery to help relieve the pressure of looking after Zac over the coming

months. This was amazing and allowed us to concentrate on caring for Finn and getting the treatments that he needed.

We turned again to the charity when Finn was being admitted in Bristol Children's Hospital for tests to see if brain surgery would be a possibility to treat his Epilepsy; the charity funded our travel and accommodation whilst we were receiving assessments and treatment. As Finn began to grow and develop his needs became more complicated and the support that we needed began to grow. Due to Finns condition he is at risk of SUDEP (Sudden unexpected death in epilepsy) and we were in a position where we were afraid to sleep. We were also chained to the house because Finn has an increase in seizures if he does not get enough sleep, so we did not go and do normal family activities because we always wanted to be able to put him down for his regular naps. Once again the The Royal Navy & Royal Marines Children's Fund came to our aid and provided a special needs Push chair that fully reclined so Finn could sleep if we went out, they also funded a Pulse guard device that constantly monitors Finn's pulse when he is asleep, the device is contacted to a wireless speaker that gives an audible warning if his pulse rate deviates from the levels that we set – waking us up to check if he is in seizure.

The support we have had from RNRM welfare was second to none in our opinion and the charitable support they were able to guide us to from, The Royal Navy & Royal Marines Children's Fund was invaluable by providing child care, financial support, allowing us to sleep at night safe in the knowledge if Finn gets into difficulty we will be aware, since receiving the pushchair we have been on several family visits to the zoo and done things "normal" families do.

ABOUT THE CEA CARD

The CEA Card is a national card scheme developed for UK cinemas by the UK Cinema Association (UKCA), formerly the Cinema Exhibitors' Association (CEA). The scheme was introduced in 2004 and is one of the ways for participating cinemas to ensure they make reasonable adjustments for disabled guests when they go to the cinema; in particular it ensures a complimentary ticket for someone to go with them.

You don't need to have a CEA Card for a reasonable adjustment to be made and cinemas still have to make reasonable adjustments. If you require an adjustment to visit a cinema because of your disability, the UKCA's policy is cinema staff should make them for you.

The card's development was overseen by the UKCA's Disability Working Group, whose members included people from the major circuits and film distributors, independent exhibitors and several national disability charities such as Action on Hearing Loss, the RNIB and the National Deaf Children's Society, along with the UKCA's specialist disability advisers.

Who is eligible for a card?

The eligibility criteria are kept under review and maybe updated from time to time; currently people who receive one of the following benefits are eligible:

- 1. Disability Living Allowance (DLA);**
- 2. Attendance Allowance (AA);**
- 3. Blind Persons Registration;**
- 4. Personal Independence Payment (PIP); and**
- 5. Armed Forces Independence Payment (AFIP).**

Additionally, limitations placed on Cinemas by their local licenses require children and young people under 8 years of age to be accompanied by a responsible person; consequently applications for cards can only be considered for people who are 8 years of age or older.

There is a small fee to pay - for more information or to apply online, please visit the website: www.ceacard.co.uk or call **023 9224 8545**.

SESAME STREET INTRODUCES A NEW CHARACTER!



Sesame Street's newest character, a little girl called Julia, is on the autism spectrum.

Julia, who "does things a little differently", has been introduced as part of a Sesame Street initiative in the US called 'See Amazing in all Children'. It is aimed at both the autistic community and the wider public. It was launched to improve public understanding of autism and challenge the many misconceptions that still exist around the condition.

Julia won't feature on the TV show but will be included in digital and printed story books, including a range of learning resources on the Sesame Street website.

Mark Lever, Chief Executive of the National Autistic Society, says 'What we like most about their approach is how it celebrates difference and shows how a little understanding can change everything. For instance, one scene in the Sesame Street storybook shows Julia flapping. Rather than giving her an unhelpful and judgemental look - as can often happen in reality - Elmo simply explains that this means that Julia is excited. It seems really simple, but things like this can make such a huge difference.

More than 1 in 100 people are on the autism spectrum, but there's still widespread misunderstanding about what it's actually like to be autistic and how challenging everyday life can be. The NAS is prioritising work with TV, theatre, art and culture, because we know they play a central role in correcting misconceptions and creating a more understanding world. Some of the biggest leaps forward have happened because of stories such as The Curious Incident of the Dog in the Night-Time and we hope that the character of Julia will have a similar effect. Autism can have a profound effect on a person and their family, but the right understanding and support from others can transform their lives."



VOLUNTEER WITH FORCES CHILDREN

We're looking for dedicated and fun volunteers to coach and support military children on the UK adventure break this summer.

The adventure break takes place from Saturday 28 May - Saturday 4 June 2016 for children (aged 8-12) who are Sibling/Young Carers.

All volunteers are vetted and trained.

Induction and Information weekend for volunteers to take place in March/April 2016, date TBC

FOR MORE INFORMATION
Visit ssafa.org.uk/shortbreaks
Email Hannah.w@ssafa.org.uk
Or call **0207 463 9275**
To request an application form
Deadline for applications is 4 March 2016

NEW LOCATION!
Kingswood
Staffordshire



SIBLINGS AND YOUNG CARERS BREAK

29 May - 4 June 2016

This is a week long residential adventure break for dependent children between 8 and 12 who have a sibling or parent with additional needs or disabilities. Children will be supported and supervised by staff and volunteers during this week long break of adventure, new friends, confidence building and fun!

FOR MORE INFORMATION

Visit ssafa.org.uk/shortbreaks

Email Hannah.w@ssafa.org.uk

Or call 0207 463 9275

To request an application form

Deadline for applications is 29 March 2016



ELIGIBILITY

- Aged between 8 and 12
- Child(ren) are dependents of a currently serving person or reservists
- Have a parent or sibling with additional needs or disabilities

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EXMOOR FAMILY BREAK

6 - 12 August 2016

This is a short break opportunity for whole families to attend together with children between 8 and 14 who have additional needs and/or disabilities.

FOR MORE INFORMATION

Visit ssafa.org.uk/shortbreaks

Email Hannah.w@ssafa.org.uk

Or call 0207 463 9275

To request an application form

Deadline for applications is 29 March 2016

ELIGIBILITY

- All children within the family applying to attend between 8 and 14 years
- Child(ren) are dependants of a current serving person or reservist
- One child attending must have an additional need and/or disability

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USEFUL CONTACTS

National Autistic Society
www.autism.org.uk
Tel: 0808 8004104

Carers UK
www.carersuk.org
Tel: 0808 808 7777

Childrens Education Advisory Service (CEAS)
enquiries@ceas.uk.com
Tel: 01980 618 244

“Entitled To”
Free and anonymous benefit checker
www.entitledto.co.uk

Forcesline
Force Line is completely independent of the military chain of command, free and totally confidential; it offers listening, information and signposting.

- From the UK: 0800 731 4880
- From Germany: 0800 1827 395
- From Cyprus: 800 91065
- From the Falkland Islands: #6111
- From anywhere in the world (call back): (0)1980 630854

[Domestic abuse: guidance and support for the Armed Forces community](#)

This new webpage was launched last year on the GOV. UK website: <https://www.gov.uk/government/collections/domestic-abuse-guidance-and-support-for-the-armed-forces-community>. It offers information and guidance for those affected by or dealing with cases of domestic abuse in the Armed Forces community. This site is for male or female victims, perpetrators who are looking to change their behaviour, military or civilian practitioners, chain of command or concerned family and friends.

LOCAL SUPPORT GROUPS, OTHER INFORMATION & RESOURCES

RAF Benson, Oxfordshire
Support Group for spouses or dependants with an additional need or disability, contact joannahoskin@hotmail.co.uk for more information

HMS Neptune
Special Needs Support Group – Families Centre, Churchill Square, Churchill Estate
Tel: 01436 679526

East Berkshire
Support and advice for physically disabled children and additional needs education
Tel: 01753 830346

RMAS Additional Needs Support Group
A support group for parents who have a family member with additional needs and/or disability has been set up on the Royal Military academy Sandhurst (RMAS.) the group meets every second Wednesday of the month in term time at the Wishstream Community Centre, RMAS. For more information call Karen Ross on 07552 861 983

Jigsaw Support Group Bovington
Jigsaw is a support group set up for parents with children who have additional needs in the Bovington Garrison area. For more information call Ashely Woodhouse on 07557 553898

If you also have a group please let us know so we can add it to our list. If you want a group 'on camp' why not get in touch with your local SSAFA Social Worker, Army Welfare Worker or NPFS Representative, or why not start one yourself? If any group requires help with setting up then please get in contact with us.

Disability Matters – elearning to inform and inspire
A free e-learning resource for the UK workforce
www.disabilitymatters.org.uk/

The directory is managed and maintained by the FANDF committee, facilitated by SSAFA however, it is your responsibility to check the information and to find out if the club, activity or service is of a high standard and able to safely meet your needs.

Inclusion in this directory is not an endorsement and we can take no responsibility for the quality of service provided by the organisation listed. Whilst every effort has been made to ensure the accuracy of information, SSAFA or the FANDF cannot accept responsibility for any errors or omissions.

CONTACT US

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