



FUNNY LUMPS

Newsletter



ISSUE 1



Meet the Funny Lumps Board of Trustees

Marion Henry, Gail Currie, David Wynne, Janice Fairbairn, Karen Ferguson.
(Not pictured – Lorna Rothwell, Dr Wayne Lam.)

Funny Lumps is a charity working in Scotland to deliver a range of support services to children under 18 (and their families) living with Neurofibromatosis (Nf) including:

- Help with education and employment
- Help accessing information
- Peer support for children and their families
- Social events.

Funny Lumps Official Launch Event!!!!

Riverside Museum,
Glasgow, 19th Oct
13.

- Official Launch
- Family Fun Day
- Sponsored Pirate Treasure Hunt

“Hi Everyone, my name is CAL...”



Message from The Chairman of the Board Gail Currie

Welcome to our first official newsletter! It has been a very interesting and exciting few months with Funny Lumps and thankfully our transition from Confer has been smooth and well received. In a short time we have welcomed our new friend CAL, had fun at the farm, met some terrific new families and have been getting noticed in important places such as the Scottish Parliament.

Our main aims at the moment are to continue to offer a good support service, move the charity forward and work towards a clear pathway of medical care for our kids. We are fortunate to have a Board made up of parents of children with Nf so we all have a common passion and I believe this will make us all the more determined in our work.

Currently we are contacting all the genetic centres to update them on our services, working with other charities and MSPS on rare diseases, learning lots more about CAL and his interesting stories and planning our official launch.

As always you can help! We receive no government funding so we rely on fundraising to continue to our work. Why not have fun with your family or friends and get involved in raising much appreciated pennies for Funny Lumps? Organise a bake sale, dress down day or get the kids sponsored to complete an interesting or exciting challenge!

The latter part of the year is shaping up to be just as productive as the earlier months and we are looking forward to what's to come!



Meet the Board of Trustees

Gail Currie - Chairman

I'm a full time Wife and Mum of 3 living in Edinburgh. Prior to starting my family, I worked in financial services specialising in pensions. My involvement with Funny Lumps began 4 years ago when my eldest Daughter Neve was diagnosed with Nf1. At a very challenging and unexpected time I was so relieved and grateful that there was an active organisation in Scotland to offer our family information and support. They have been there from day 1 and every meltdown since!

It is a privilege to be part of the team and I greatly enjoy the work that I do within the charity, it is both productive and rewarding. As Chairman, I think it essential to work closely with Karen (our Charity Manager) as well as my colleagues on the Board of Trustees, to make sure we are providing a good support service to our families, raising awareness of the condition, moving the charity forward and working on the important issues affecting children and their families living with NF in Scotland.

Neither of my roles as Wife/Mum or Chairman comes with annual holidays or flexi-time however the benefits are so much more. When I am not doing either of these, I also enjoy reading the classic novels, going to the cinema, shopping, walking the dog (and the kids) and catching up with friends and family.



Karen Ferguson – Charity Manager

I am the Charity Manager of Funny Lumps and the mother of two grown up sons, the oldest of whom has Nf. I have worked for the last fifteen years in the Nf community. Initially with the Neurofibromatosis Association (now the Neuro Foundation) as Development Manager for Scotland and then set up the charity Confer which then evolved into Funny Lumps. My hopes for the future are for every child with Nf to reach their full potential both educationally and socially and to be able to access the health care necessary for their lives to be as pain free as possible.



Marion Henry

I have four sons, one of whom has Neurofibromatosis (Nf1). My interest in Nf1 stemmed from this situation and led me naturally into my current occupation and studies. I am a Chartered Teacher and I also have a Master of Science Degree (MSc) in Educational Support. My Nf1 study and materials were developed over a five year period of Educational Research through my MSc study. Advice and materials are matched to each child's particular needs and this intervention is making a real difference. Educational advice, support and information are offered to fellow professionals and parents through the 'Funny Lumps' Charity. My intention is to share this information widely, thus raising the profile of Nf1 and helping children with Nf1 to achieve success in their learning.



Dr Wayne Lam

Dr Wayne Lam is a Consultant Clinical Geneticist at the SE Scotland Genetic Services based at the Western General Hospital, Edinburgh.



David Wynne – Child Protection/Secretary

I am the Child Protection Officer and Secretary of Funny Lumps and currently a Warrant Officer in the Royal Navy working for Flag Officer Sea Training. I have two daughters, the youngest has Nf1. Funny Lumps supported my family from the beginning and are continuing to do so. I am fortunate to be working with a fantastic team and supporting some fabulous children and their families.



Janice Fairbairn

Hi I'm Janice, I come from a 3 generation family with Nf – my dad, myself and sister and my two daughters aged 11 and 13. Although I only have the lumps and cafe au lait marks and my daughters so far only have the cafe au lait marks it's so reassuring to know we have Funny Lumps (and previously Confer) at the end of the phone. I'm honoured to be part of Funny Lumps and look forward to helping take this new charity forward.



Lorna Rothwell – Fundraising Manager

I am 39 and I have 3 boys and 2 stepdaughters. I first got involved with Confer when my middle son Jon-Paul was 4 years old and newly diagnosed with Nf1. That diagnosis was devastating for myself and his dad and we were struggling with it all but with Confer's help and now Funny Lumps, we have learned a lot and received lots of support. There is always someone there willing to offer support/help and advice with problems or worries. I became a trustee of Funny Lumps to enable me to give back to the charity and offer support to others.



"We all had an excellent day out at the farm, kids especially loved the animal handling session and pony rides, food was excellent too. Great having a chat with other parents. Fab job. Thank you."

Family Day at Gorgie Park Farm

29th of June didn't look a particularly summery day. Bit grey and overcast and then some drizzle. Typical Scottish summer!!!! However, the weather didn't stop our families getting to Gorgie Farm by bus, train and car and having a fantastic day out!!!!!!

This was our third year at the farm and as usual there was lots to see and do for the kids (and the adults).

Pony rides are always popular as is the pet's corner. It's a great place to get to hold the animals under the expert supervision of the staff. The rabbits are always a favourite with the kids.

Some families have been coming since the start but for others it was their first chance to meet other kids with Nf and make new friends.

While the kids were busy, the parents had a chance for a cuppa and a chat. It's always reassuring to meet other parents and swap experiences.

Here are some of the things our families had to say about their day out:

"Every year we look forward to the visit to Gorgie farm. It gives Megan the chance to meet other kids who have the same condition as her. Even though she can't touch the animals because of her allergies she still loves going. It also gives me the chance to talk to other parents who have kids with Nf. Megan loves looking at the animals but the one thing she loves most is the horses. She loves being able to go on them as well as playing in the park with the other kids."

"The farm was an amazing day. Meeting all the other families that are affected with Nf and swapping stories about our kids and how they deal with things was great. The kids loved meeting new friends and seeing the animals".

Not much more anyone can say than that!!!! Thanks to everyone for coming and making it such a successful day and we are already looking forward to next year!!!!!!

Recent Fundraising

Figure 1 shows Jon-Paul presenting Karen Ferguson with a cheque for £126 from a fundraising event at his Primary School.

Figure 2 shows David Wynne at the summit of Whenside during the Yorkshire 3 Peaks Challenge, raising £750 for Funny Lumps.

Figure 3 shows Kyle with a fantastic purple cake which he raffled off a school to raise an amazing £141.

Figure 4 shows Lorna Rothwell and Lee Alves who raised £141 at Asda in Livingstone along with Gail Currie, Karen Ferguson, Janice Fairbairn and Elise MacGregor.



Fantastic Fundraising



Figure 1 – Jon-Paul, at his Primary School.



Figure 2 – Yorkshire 3 Peaks



Figure 3 – Kyle Huge cake raffle



Figure 4 – Asda Livingstone



WORKSHOPS FOR PARENTS

Having a child with Nf continually throws up questions.

All kids with Nf are different. Even within the same family two affected children will be different.

If as a parent you also have Nf then that can also make a difference.

A constant question is "Is that because of Nf?" Every parent would like an expert on the condition to be on hand 24/7 to answer their questions as they arise. While we can't offer a 24/7 expert what we can offer is a series of workshops aimed at answering your questions about your child with Nf. There will be an "expert" at each one to give you advice and information and to answer any questions you may have.

The topics will be:

- **Genetics and all things medical**
- **Education**
- **Behaviour**
- **Autism and ADHD**

These workshops have been funded by **Awards for All** so there will be no cost to the families. Dates and venues will be published soon.

REGISTER WITH EASY FUNDRAISING – RAISE FUNDS WITHOUT TRYING THIS CHRISTMAS

How it works

easyfundraising.org.uk helps **charities, schools, sports clubs, community groups**, and other **good causes** to **raise money** when their supporters **shop online**. So far they've raised **over £5 million** for causes throughout the UK.

It works in a **similar way to many other loyalty shopping sites**, but instead of earning points when you shop, **you raise a donation for your cause instead**. It's as simple as that!

You can shop with **over 2,000 well known stores** and each will **donate up to 15%** of what you spend. For example, John Lewis will donate 1%, Amazon 1.5%, The Body Shop 6%, some insurance retailers will even donate up to £30 simply for taking out a policy with them!

Cross Party Working Group

Karen Ferguson and Gail Currie are now part of a Cross Party Working Group on Rare Diseases that has been created with the aim of asking questions and raising awareness in the Scottish Parliament. The group consists of members from various Rare Diseases Organisations, 7 MSPs, medical professionals and Natalie Frankish (Scottish Development Officer RDUK). A workshop was held in July 13 to discuss aims and objectives and to discuss issues with care, diagnosis and medication. The group will meet 4 times a year and hold workshops twice a year. Work is progressing in the hope that more medical professionals will join the group with a keen interest in genetics.

Funny Lumps Educational Materials and Continued Nf1 Study

I have been working voluntarily on the Board of Trustees for a number of years, supporting those affected by Neurofibromatosis Type 1 (Nf1) and their families. I know how it feels to have a child with Nf1, feeling helpless and unable to find answers to an array of questions. Very few people know enough about Nf1 and so rather than keeping looking for those who could possibly answer my questions, I decided to start finding out about it for myself. As a Primary School Teacher, I was aware of how little was known about supporting pupils with Nf1. This need for information led me naturally into a study which has helped me to understand Nf1, how it affects the body and ultimately, how it can affect learning.

Nf1, can impact on physical wellbeing, behaviour and learning. I found it bewildering that there was nobody out there to help and to advise me about what to do, to help my child to learn. I knew then that I needed to search for these answers. It was an easy decision to research the Teaching and Learning of pupils with NF1. My study took five years to complete and opened a whole new area of Professional Development for me as a Teacher, giving me the essential information that I needed as a Mum. At last, I had answers and as I was already involved with 'Confer', our Nf1 charity in Scotland, I could have the opportunity to help other children, who might also need help with learning and/or behaviour modification. I had learned a great deal and I was glad of the opportunity to share my research findings, materials and strategies with others. I was able to offer advice and to support fellow professionals in schools and my input was welcomed. I went into schools, sharing my skills and helping to make teaching and learning more effective for Nf1 pupils. This new information was making a real difference.

Through my Educational Research studies, I had developed support materials to help pupils to achieve in school, helping to break down barriers to learning. Educational Support for pupils with Neurofibromatosis Type 1 takes many forms. Initially, there needs to be a referral request from either the school or the parent, seeking help for the child who is experiencing difficulties in their learning, as a result of having Nf1. At this point, in response to this request, Karen Ferguson who is our Educational Advisor, will usually offer to make a school visit. Advice at this stage can give relief to parents or guardians, who may be feeling very alone and concerned for their child. Schools are also appreciative of this new contact with our charity. Essentially, 'Funny Lumps' offers helpful advice and simple answers to help parents, children and schools to understand what Nf1 is and how to support Nf1 pupils in overcoming their barriers to learning. Sometimes general advice and support is enough. At other times, more specialised advice is needed. That is where my strategies, advice and support materials are offered. These Educational Support materials and advice sheets were designed to be prescriptive, matching each child's particular Nf1 needs. There is no 'one size fits all' answer, as every child is different. Parents and schools may just want Nf1 information, or they may need a higher level of support and advice. Karen is often invited to multi-agency meetings, helping all in attendance to understand what Nf1 is and how it can affect the child.

In my role, I offer advice and Specialist support voluntarily, to fill a void which can surround this often misunderstood, genetic condition. I just wish that I knew then what I know now and that there had been more advice available when I needed it. I know that Karen feels exactly the same! That would have been a relief. At that stage, with no available support, we supported each other, comparing and talking about the situations which we both faced. Not surprisingly, we were both experiencing the same issues. My hope is that through 'Funny Lumps', we can help to make the understanding and the overcoming of difficulties caused by Nf1, much easier. We need to remove the myths and offer real answers to very real questions about Nf1.

Having completed my initial research into Neurofibromatosis (Nf1), I realised that there is still so much to do and there have been many opportunities to develop my research. I needed to expand my work further and so I have now commenced a new study, which moves into new area. I am now examining the effectiveness of giving initial advice to parents and carers, of making a school visit, of using my materials and of liaising with staff in schools. The current emphasis in Education is focussed upon 'Getting It Right For Every Child' (GIRFEC), making this an ideal time to pursue and to develop this research. In Scotland, every child has a wonderful opportunity to learn through the 'Curriculum for Excellence' which offers exciting learning opportunities for all children in our schools. This new research will give me valuable results, based upon the real learning opportunities offered to our Nf1 children in our schools. I will then collate and feedback this information to 'Funny Lumps' helping to evaluate, to adapt and to implement any required changes in Nf1 pupil support. This work will provide valuable evidence about the effectiveness of these materials and strategies, examining the support work completed whilst working collaboratively with Teachers, schools and parents in supporting these Nf1 pupils. It will also enable me to gauge the level of satisfaction felt by families, when they realise that they have the support that they need. Families will also be able to highlight any areas of support which they feel could be offered. This will be extremely valuable information.

I will be asking some of our families to respond anonymously to a variety of questions about the support given through our 'Funny Lumps' Scottish Charity. I need to examine the effectiveness of my support materials, the differences made by the support given and the resultant effects upon the Nf1 child's learning. It is also important to take note of the responses from the child, the family and the School, asking them to share their thoughts, opinions and information. This work is intended to help us all to understand even more, about the difficulties encountered by the Nf1 child in school. I will compile my study report, looking carefully at this specific, targeted support and I will examine the evidence from all who are willing to participate and to share their experiences.

I do hope that many of you will respond to my questionnaires. This will help me to develop future support, based upon your responses and valuable feedback. I will also ask some parents if they might agree to a short interview about any help given. In addition, I will contact some Schools and Class Teachers to discuss the help given, asking if we can offer them more support and what type of support that they might need, either now or in the future. Essentially, I want to offer the best service possible through 'Funny Lumps' and with Karen's expert school visits and support, I feel sure that we can do that very effectively. My study is ongoing, so watch this space for more information soon!

I am looking forward to hearing from you!

Marion Henry (BEd Hons; MSc; Chartered Teacher).

SUPPORT FUNNY LUMPS 'THUNDER CLAP' – LETS RAISE AWARENESS TOGETHER

How does it work?

If enough people support it, Thunderclap will blast out a timed Facebook Post or Tweet from all your supporters, creating a wave of attention. The Thunder Clap is timed to coincide with the Launch Event **1100 19th October 2013**. **CLICK THE LINK, CLICK SUPPORT ON FACEBOOK OR TWITTER, SHARE!** It's easy and costs NOTHING!!

<https://www.thunderclap.it/projects/5055-funny-lumps-official-launch>Currently

Funny Lumps

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Facebook: <https://www.facebook.com/pages/Funny-Lumps/257997900940296?fref=ts>

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