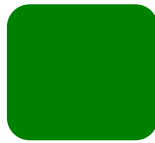




Inform



SDEF Voice



Scottish Disability Equality Forum Monthly Newsletter

Issue 45 - June 2017

Dear Member

Welcome to the latest issue of SDEF Voice, your monthly newsletter from the Scottish Disability Equality Forum. In this month's issue, you will find information about:

- Joining the SDEF Board
- Providing feedback for Scottish Government digital services
- Immunodeficiency – My Journey
- NHSinform

If you have anything you would like the SDEF community to read about in next month's issue, make sure you get in touch with us.

Best wishes,

SDEF team



SDEF News

This month we said goodbye to our administrator Maureen Bennison, who has been a big part of the team here at SDEF.



Maureen joined the team as a temp, but soon became a permanent member of staff and many of you will know her as the first voice you hear if you contact our offices!

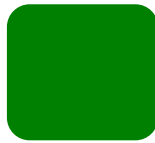
Maureen's background is in politics, and her wealth of knowledge in this area has really helped SDEF make more political in-roads. For example, Maureen was instrumental in helping SDEF put together our own manifesto, and she organised our survey on accessibility which we sent to all MPs and MSPs.

She also organised our consultation work, gathering your feedback and passing this onto the Scottish Government, and others.

Maureen was also our resident Easy Read expert, helping to produce documents and information in an accessible format. The rest of the team will now carry on Maureen's legacy and continue to offer a high-quality service.

Maureen has left us to become a full-time councillor for the Bannockburn ward in Stirling, but she remains a member of SDEF and we're sure to see her again at events and meetings.

We wish her all the best!



Join Our Board!



Scottish Disability Equality Forum is seeking to recruit volunteer Board members, who oversee the work of our dedicated staff, and develop our strategy and vision.

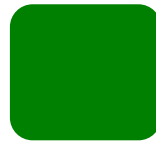
The Board meets seven times per year in Stirling or Alloa. Travel and all other expenses are paid to attend meetings from any part of Scotland.

We are an equality organisation and we very much welcome applications from all communities, and in particular from disabled people.

Here is the application pack:

- Board Member Application Form
- Board Member Role Description
- Board Member Skills Audit
- Equal Opportunities Monitoring Form

More details are available from Morven Brooks, Chief Executive Officer
morven.brooks@sdef.org.uk Tel: 01259 272063



Scottish Disability Equality Forum - Annual General Meeting (AGM) 2017

We are pleased to announce that The Scottish Disability Equality Forum Annual General Meeting (AGM) 2017 will be held at the Perth Concert Hall, Mill Street, Perth, PH1 5HZ on Tuesday 12 September 2017 at 10.00am.



This year we will have a marketplace of stalls.

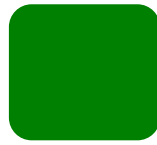
So far we have the following organisations: The Scottish Parliament, ILF Scotland, Disability Information Scotland, Scottish Personal Assistant Employer Network (SPAEN), Humanism in Scotland, Stirlingshire Voluntary Enterprise and Disabled Go. If you would like to book a stall at our event, please contact us for further information.

We will also be running four workshops on Inclusive Communication, Accessible Travel, Inclusive Design and Disability Safety. This is an opportunity for us to share with you the progress we have made on these projects, however more importantly for you to provide us the valuable feedback we need.

If you would like to attend the SDEF AGM 2017, please complete the booking form sent to you or contact us to request a booking form. Please return your completed booking form no later than Wednesday 16 August 2017 to allow arrangements for communication, access or dietary requirements. Please send your form to the address below or email maeve.bain@sdef.org.uk

You can also register to attend by completing our online booking form: www.eventbrite.co.uk/e/scottish-disability-equality-forum-agm-2017-tickets34100364107

We look forward to welcoming our members!



Do you want to help improve the accessibility of the Scottish Government websites and digital services?



**The Scottish
Government**
Riaghaltas na h-Alba

The Scottish Government is always working to make websites and digital services as accessible and usable as possible. We are looking for volunteers with disabilities and who use assistive technology. We would like to create a user community that could help by giving feedback on projects where invited.

Activities would range from a one-hour interview in your home or at a Scottish Government office, reviewing a website at home and providing feedback by email or completing a short survey. The activities may include a reward for taking part and expenses may be refunded.

If you would like to be included in the user community, or if you require any more information, please email James Davidson, SDEF Online Access Worker: james.davidson@sdef.org.uk



Weekly Poll - June Roundup

Have Your Say...

Gathering the views of disabled people in Scotland



The Weekly Poll is a simple YES/NO question published each week on our Your Say on Disability website: www.your-say-on-disability.org.uk/ There is also an opportunity to leave a comment on the chosen topic. Thank you to everyone who completed our Weekly Poll during the month of June. Below is a summary of the three questions we asked during June, along with your responses.

Accessible Voting

Question: Do you think voting is accessible in Scotland?

Your feedback: Yes- 36% (10 respondents) No - 64% (18 respondents)

Key comment: "Physical access can be difficult. Access to communication support, better acoustics and hearing loops etc never seem considered either."

Carers Allowance

Question: Have You Applied for Carer's Allowance?

Your feedback: Yes – 27% (6 respondents) No – 73% (16 respondents)

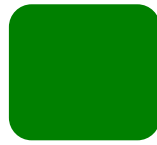
Key comment: "The allowance is too low to allow for carer's to only work part time."

Accessible Parking

Question: Do you think parking, including parking on pavements, at dropped kerbs and double parking is a problem in your area?

Your feedback: Yes – 93% (28 respondents) No 7% (2 respondents)

Key comment: "Parking on pavements, at dropped kerbs and double parking is a problem that I regularly meet as I go about my job in the community, which can be very frustrating."



Immunodeficiency – My Journey

The following article is by SDEF member Carole, who has very kindly written an article to raise awareness Immunodeficiency.

Twenty years ago after major surgery I developed oral fungal infections which subsided with treatment but returned once medication had stopped. I attended clinics in various NHS specialities but the infections persisted, eventually I went privately to see a Consultant Dermatologist who diagnosed chronic mucocutaneous candidiasis (CMC) – a t-cell primary immune deficiency (PID). Treatment in my case was high doses of anti-fungal drugs and I was advised there was no cure – only symptomatic relief achieved by daily medication. At that time there were no support groups available, no information on the internet and I have never managed to find another adult with the same PID. Some medical professionals in clinics I attended doubted the existence of the condition so I copied an article on CMC I found in a medical journal to prove it was genuine.

Fast forward 20 years – symptoms of my CMC are deteriorating - I now take unlicensed drugs and have regular IV anti-fungal treatment in hospital. The other serious health conditions I have since acquired including primary Addison's disease (adrenal gland failure), insulin-dependent diabetes and previous pseudomonas in lungs are related to CMC. I'm prescribed what is termed a 'poly-pharmacy' of medication and have many medical appointments to hospital clinics and my GP. Unfortunately I had to retire from my job due to frequent hospital admissions and susceptibility to infection. Every day I suffer varying degrees of pain and discomfort – depending on whether it's a good or bad day and a lot of time is spent taking medication, self-injecting and trying to manage my symptoms.

Thankfully UK Primary Immunodeficiency Patient Support (UKPIPS) is a lifeline for me - they understand the special challenges and isolation that comes with PIDs. In conjunction with my Immunologist I have agreed to participate in medical research for my PID, hopefully by doing this there may be a better prognosis for future generations.



UKPIPS - Primary Immune Deficiencies



Primary Immune Deficiencies (PID's) are a group of genetic diseases that stop the immune system from working properly, such that the body cannot effectively combat pathogens - things which invade us and do us harm. People with a PID get more ill, more quickly, than others. There are currently about 4,000 people in the UK who have been diagnosed with a PID and most have become unwell as adults.

How people are affected depends on where and how badly the immune system is damaged. Some have mild symptoms, such as having more sinusitis than most "well people", some are affected to the extent that they will die as a direct result of their PID. The severity that people experience ranges between these two extremes. The most common forms of PID are Primary Antibody Deficiencies. These mainly affect how people combat bacterial infections. Other types affect how people combat viruses, fungus infections and some mean that people cannot fight any type of infection.

The immune system is one of the most complex systems of the body and relies on many parts of it working together to make sure invaders are recognised, attacked and destroyed as quickly as possible. Some parts of the immune system are well known, such as the skin or antibodies, but most people, including most Doctors, will not have heard of things like natural killer cells or the complement cascade. Many have heard about the "baby in the bubble", a child who had severe combined immune deficiency (SCID). Sadly, this is the only type of Primary Immune Deficiency that most Doctors remember learning about in medical school, because of this many believe the only types of Immune Deficiency are SCID or AIDS. The time it takes for people living with a PID in the UK to be diagnosed is about seven years.



The main symptoms people have before diagnosis are repeated infections that go away with treatment but then return soon after the end of the course of treatment. Many people experience accusations of hypochondria before they are diagnosed and shamefully, some after their diagnosis has been made. Parents of children living with an undiagnosed Primary Immune Deficiency can be accused of being “anxious parents” and even of having Munchausen’s By Proxy. By the time of diagnosis many people have lost faith in a medical system that seems cruel. However, those lucky enough to be treated by a Clinical Immunology Team gradually learn to trust and respect those with the knowledge to ensure that their quality of life is as good as possible.

Clinical Immunology is a very young science. The first Primary Immune Deficiency was discovered in the 1940’s. When you compare that with something like haemophilia which was known about in the reign of Queen Victoria, it brings it into perspective.

Currently there are no cures for PID’s and treatments cannot replace a functioning immune system. Most people will still have breakthrough infections and other problems caused by their broken immunity. Treatments vary depending on the type and severity of the deficiency; the most common treatments range from taking prophylactic antibiotics (taking antibiotics all the time to ward off infections) to having replacement immunoglobulin therapy. Immunoglobulin replacement is a blood product that can be given either intravenously or subcutaneously. Many people do their infusions at home with the help of a partner.

If you would like to know more about PID’s, please contact UKPIPS – the patient support group run by PID patients for PID patients. Call us on **01386 421228** or email us at admin@ukpips.org.uk or visit our website at www.ukpips.org.uk

UKPIPS also has a 'closed' Facebook group for Scottish PID patients called UKPIPS Scotland.



Disabled Access Day is returning in March 2019!



March 2019

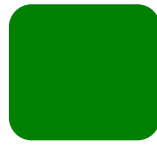


Disabled Access Day has gone from strength to strength over the three years that it has been taking place. Hand in hand with that success comes the challenge of maintaining the momentum and finding the resources to make it all happen.

After some degree of soul searching, consultation and much discussion we have decided to make the event biannual. It gives us, participants, and all those involved time to plan and gather together the resources to continue making Disabled Access Day the amazing event that it has become. We can't do it without you, and we are extremely grateful to those who have joined us on the journey for the past three years.

We are delighted to announce the next Disabled Access Day will take place in March 2019. We look forward to sharing the fun, excitement and celebration that comes with it with everyone.

If you would like to sign up to take part in the March 2019 celebrations, please click [here](#) to register your venue, organisation or charity. We cannot wait!



Call on Scottish Government to seize once in a generation opportunity to tackle accessible housing crisis



Launching “Our Place: Our Space”, a report into the housing needs of disabled people, Inclusion Scotland has today called for the Scottish Government to seize the opportunity presented by their plan to build 50,000 new homes, by ensuring that they are built to be fully wheelchair accessible, or easily adapted to be so.

Evidence of the scale of the problem is overwhelming. Around 14% of households in Scotland include someone who uses a wheelchair or mobility aid. However, only 0.7% of Scottish Local Authority housing stock, and 1.5% of Housing Association property, is accessible for wheelchair users. And there is no definitive information about the number of accessible or adapted houses in the Scottish private sector.

Dr Sally Witcher, Chief Executive of Inclusion Scotland said:

“Being unable to buy or rent an accessible home literally imprisons disabled people - in their own homes, in hospital, or in residential care against their will. This leads to poor health, intolerable stress for families and the need for additional social care support.”

“The current failure to provide an adequate supply of wheelchair accessible homes in Scotland creates a ticking time bomb with significant cost implications for services, housing and support all across Scotland.”



“If

we are committed to making Scotland fairer for disabled people we need to address the chronic shortage of wheelchair accessible housing immediately.”

By documenting disabled people’s housing experiences, “Our Place: Our Space” exposes the myth that current design and building standards and the provision of adaptations in Scotland are meeting the housing needs of disabled people.

As Dr Witcher makes clear:

“Most disabled people live in homes that cannot be adapted. While the newer so-called “Barrier free” homes offer choice for some, they fail to meet the access needs of many wheelchair users.”

The current situation is expected to get worse unless action is taken soon as the population ages and demand increases. In 20 years there will be over 250,000 more households in Scotland including someone aged over 65 years old, and of these just under half will include someone over 85 years. 75% of these households are currently living in homes which cannot be adapted for their expected needs as they age and certainly not if they become wheelchair users. Statistically around 10% of the over 65’s and 25% of the over 85s will use a wheelchair at least part of the time.

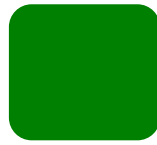
Dr Witcher added:

“With the Scottish Government’s commitment of £3billion towards building 50,000 new affordable homes we need to see an explicit commitment to focussing a fair share of this investment on increasing the supply of wheelchair accessible housing

“A 10% target for new homes is the bare minimum required to tackle the shortfall – and it needs to start now”.



Inform



Would you like to take part in a Patient and Public Involvement Group?

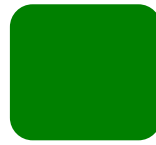
Message sent on behalf of University of Stirling



The University of Stirling are looking for participants who have experience of a health condition or illness, or experience of using health or social care services; those who have a loved one or family member who has had a health condition or illness, or has used health or social care services; those who work in health or social care services, and anyone else with an interest in health and behaviour-related research.

If you are interested, please click on the link below for more details and details of how to register.

<http://www.stir.ac.uk/sbmrg/patientandpublicinvolvement/>



NHSinform - Redesigned



Finding the right health and care information can make a real difference to how people manage their wellbeing. Making information accessible, quality assured and up to date helps people to make positive choices.

The NHSinform service is Scotland's dedicated resource offering up-to-date facts on health, services and campaigns. It also has a wealth of information on tests and treatments, healthy living and support which is available online, over the telephone or via webchat.

Check out the newly redesigned website at www.nhsinform.scot

One of the many great features of the new website, is that users can interact with other people and medical professionals on webchat and find out about specific conditions in community forums.

NHS 24 Head of Health Information Services, Lynne Huckerby said:

"This is an exciting development for one of NHS 24's key services. It aims to put the needs of people first.

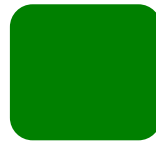
"New features such as webchat, will allow people to access the information they really need, quickly and easily.

"Our new digital service will make it much easier for people to access information in a central place and essentially it will give them the freedom to manage their own healthcare.

"NHSinform allows everyone to make positive choices about their own health and wellbeing as well as information to help carers."

The redesigned website aims to be more personal with easy speech functions, as well as reading and translation tools.

Want to try the new service? Log on now to: website www.nhsinform.scot or call: 0800 22 44 88



SDEF Easy Read Service

The Scottish Disability Equality Forum provide a professional and efficient Easy Read service to all sectors, as part of our commitment towards improving access to information for all.



What is Easy Read?

Easy Read is an accessible format that makes written information easier to understand. The Easy Read format is easy to understand because it uses simple, jargon free language, shorter sentences and supporting images.

Why produce Easy Read documents?

Easy Read documents make information more accessible to people with learning disabilities. They can also be useful for people with other communication difficulties including:

- acquired brain injury
- dyslexia
- people with hearing impairment whose first language is British Sign Language (BSL)
- people who do not speak English as their first language
- people who find reading difficult
- people with cognitive impairments such as dementia.

The Equality Act

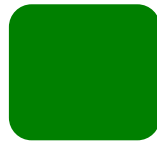
The Equality Act (2010) requires organisations to produce information in an accessible format. Easy Read can ensure that disabled people have equal access to information and are not discriminated against.

Who do I contact?

For more information about the Scottish Disability Equality Forum Easy Read service, please contact us by telephone or email:

Telephone: 01259 272064

Email: admin@sdef.org.uk



Your Membership Matters

Your

Membership

Matters



Below is a reminder of what we offer our members. If you would like to find out more then please contact us.

Support and Signposting

We answer many member enquiries and signpost them to the appropriate organisation, individual or information source.

Networking Opportunities

We make introductions to key decision makers and contacts and make sure members have frequent opportunities to meet and network with relevant audiences. We help members make the right connections.

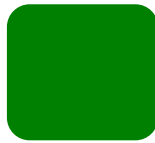
Your views, experiences, and expertise

All our policy is formulated directly from our member's views, experiences, and expertise. We believe that our members are the experts.

We respond to all relevant Scottish Government, parliamentary, think tank and other consultations. We regularly ask our members for their views on many diverse policy issues which then directly feeds into our policy work and government consultation responses.

Information Leaflets

We provide information leaflets on the projects we are working on. You will receive a copy of our leaflets in your Members Welcome Pack. If you require any additional copies, please call the office to request this or alternatively they can be downloaded from our website.



Our Sponsors

Scottish Disability Equality Forum would like to take this opportunity to thank our sponsors whose logos are featured below. We are very grateful of their continued support for the work that we're doing.

Did you enjoy this newsletter? Do you have any suggestions or comments? Do you have an article you would like to appear in the next issue? Get in touch with us if you do. Our contact details are at the bottom of this page.



Yooz
Reuse & Recycling



Humanism in Scotland



Blackwood
homes | care | support



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