

Money Matters...

Benefits... can you help?

Over the last couple of years we have completed ESA and PIP for our son and wanted to hear how you, our members, are managing and what tips we can pass on to other parents.

Have you been successful in your claim?
Did you get help with filling out the form?
Did you have a face to face meeting (how was that)?
Were the DWP helpful?
Are you getting less or more?

With all the current changes in benefits and the roll out of universal credit please get in touch with your experiences; we can share these points with other families who may be just starting this journey.

A few tips that you may find helpful which we have discovered

1. Do not be afraid to ask for help, your friends and family, professionals that know you or your child the best.
2. Fill in a paper or online version of the form so you get plenty of time to formulate your responses, don't get sucked in to doing it over the phone.
3. Take your time to fill out the forms. Remember that the benefits agency do not know your child or you.
4. Don't just tick the boxes you also need to describe how the WDS disability affects you or your child so they can understand the claim better, don't describe the best days.
5. Think about safety, you or your child may be able to perform the task in the question BUT would it be safe to themselves or to others to do so? e.g. crossing the road. If you think safety is an issue say so, we did.
6. Keep copies for your completed forms.

With all the current changes in benefits and the roll out of universal credit, please get in touch with your experiences.

You can email Vanessa at National.Contact@wdssg.org.uk

You can find out more about benefits you may be entitled to www.contact.org.uk/advice-and-support/benefits-financial-help/benefits-and-tax-credits/

Need a free bank account?

If you're creating a Family Trust or you work for a small, not for profit organisation and need a new bank account or the one you currently have is too expensive, see what the Co-operative Bank has to offer with their **Community Directplus** account, you may be eligible. Go to www.co-operativebank.co.uk/business/currentaccounts/community-directplus



..raises money as you buy!

Did you know that you can raise money for the group whenever you make a purchase from Amazon by using the Amazon Smile website? We are now registered with Amazon.

AmazonSmile is a website operated by Amazon with the same products, prices and shopping features as Amazon.co.uk. The difference is that when you shop on AmazonSmile, Amazon will donate 0.5% of the net purchase price (excluding VAT, returns and shipping fees) from your eligible AmazonSmile purchases to your nominated charity.

Just go to www.smile.amazon.co.uk and sign in with your Amazon account details or register and nominate the "Worster-Drought Syndrome Support Group" as your chosen charity. Buy from Amazon as normal but via the Amazon Smile website (they will remind you if you forget, which is useful).

Try these useful benefit sites..

www.turn2us.org.uk

Turn2us helps people in financial need gain access to welfare benefits, charitable grants and other financial help – online, by phone and face to face through our partner organisations.

www.entitledto.co.uk

The leading provider of online benefit calculators in the UK today. They help people determine what they can claim from national and local government via the self-serve calculators. The calculators are authoritative and accurate and we are entirely independent of government. They provide a reliable estimate of benefit entitlements based on their in-depth knowledge of the UK's social security system. By using their online benefits calculators, users can determine whether they are receiving the right amount of money in their benefit claims, whether they are eligible for other types of benefits, as well as understand what their position will be as Government welfare reforms take effect.

www.betteroffcalculator.co.uk

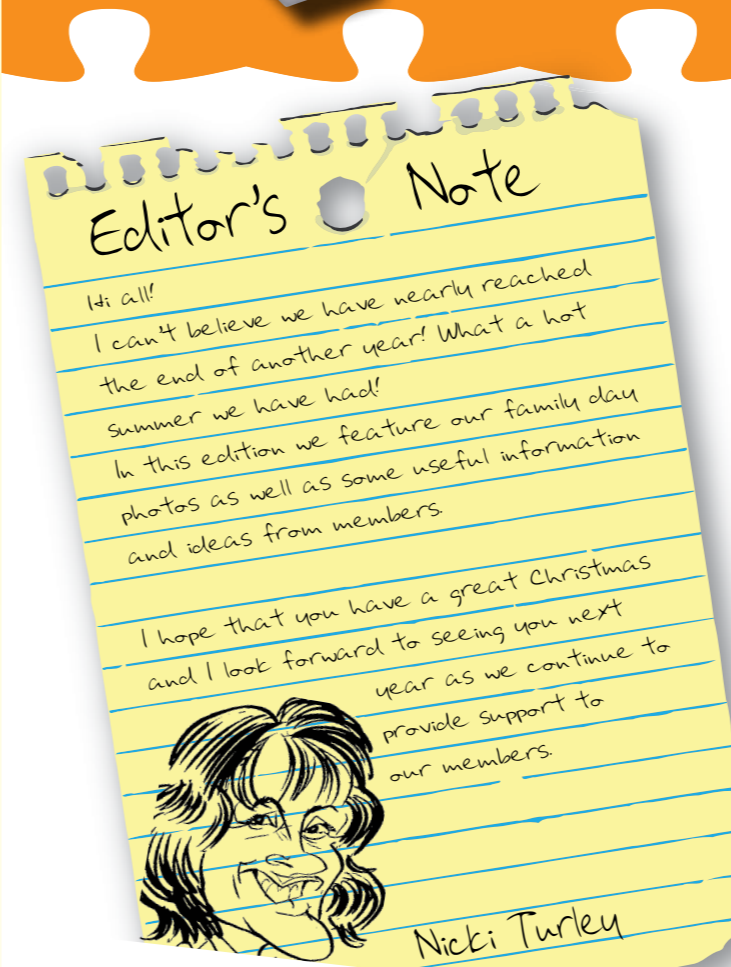
A Benefit and Budgeting Calculator that you can:

- Find out which welfare benefits you could receive
- Know how your income will change with Universal Credit
- Compare your income under the current system and Universal Credit
- See how much income will be left after paying your housing costs
- Access links to claim for benefits



Link

NEWSLETTER WINTER 2017



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STILL AVAILABLE
Order your usual pack of Christmas cards and you will also receive an extra design from last years competition winner - Jack Sugden.

STILL ON SALE

You can pay by cheque, Paypal or BACS transfer. See our website for more details and an order form or contact Nicki at secretary@wdssg.org.uk

* 1 pack £2.60 - add 30p for each extra pack ordered

£3.00 per pack + postage*

Don't forget to send your articles or any news that you would like to see in future issues to: secretary@wdssg.org.uk

Please let me know if you have anything that you would like to share with other members.



Affiliated to Contact a Family and Rare Diseases UK

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All information in this leaflet is correct at time of going to press.

linking members together

www.wdssg.org.uk

From the Chair

It was great to return to Thames Valley Adventure Play Park again this year, I always have a great time meeting families old and new. I have felt that things haven't changed much within the group over the last year or so, new ideas and suggestions would be welcome.

On a personal level, I have been struggling with planning and understanding what the future holds for me with so many changes to the benefit system, I have been forced into managing and employing my own carer at home which has been a struggle for me. I have felt, even with understandable speech, I am not always listened to and that I'm wasting money and time I don't really have. I know this must be a concern for your children as they grow up and how they will manage and cope with everyday life.



I know from my own experiences that things do work out in the short term but like most things, being able to plan long term is always difficult, disability or not.

I am a great believer that together as one family we can help each other. Sharing your stories, no matter how large or small, helps others. I hope that the group can offer a safe place for you to be able to do this.

It is important that we grow and allow your children and young adults to reach their full potential. I would very much like to hear from you so we can build up a history of case studies that we all can share. One thing that has always been clear to me when listening to parents is just how many of our experiences are the same. I am hoping by sharing them we can gain help from reading them.

Mark Mayer

WDS Family Case Histories

Introduction

At this year's Family Day it was suggested by a member that perhaps the members themselves would like to write their stories and experiences of WDS and how it impacts them. They will be called "Case Histories".

A simple template that we could all loosely follow will give a common look and feel. Once completed these case histories will be published on the WDSSG website for all to read. As it's a public website, these case histories will be available to anyone and everyone in the world, hence the need for guidance notes.

The committee discussed this at a recent meeting and thought that they should be anonymous, so the histories will be known as WDS Case History (Number 1,2,3...) We do not need names, instead we will use 'Child' or 'Subject' followed by the case history number or an initial like M or if you are writing about yourself the I, Me etc. could be used. Please do not include any pictures that may identify you or your family.

If you choose to write a history, please contact John Butt at johnb@buttsco.co.uk and I will allocate you a case history number and then upload your completed history to the website and any further updates you would like to make or remove.

We have chosen to make the template based on the following age related stages that we hope you will all recognise. If you choose to do something different or suggest a change please contact John Butt.

Dates are only a guide, each case is different but it will be better if they all have a common look and feel.

John Butt

Things to think about

Please consider these at all stages as things change for better or worse plus anything else you feel will be of help.

- Pregnancy problems
- Delivery issues and was it full term.
- Key developmental stage points reached or not.
- Learning difficulties.
- Age of diagnosis, were they misdiagnosed.
- Feeding problems and how they were mitigated.
- Babbling, talking, speech issues and how they were mitigated.
- Crawling, toddling, walking
- Benefits, including carers benefits.
- Fits, when they started.
- Choosing schools, colleges etc.
- Bullying
- Impact on the rest of the family
- Transport, adaptations, special conversions required, blue badge...
- The Early years (-9 months to 3 years)
- Preschool
- Primary
- Secondary
- Transition
- Further education
- Living independently
- Living with Worster-Drought Syndrome
- My View
 - From a Parents perspective
 - As a sibling

This years Family Day was a scorching success!

This years family day was a scorcher and thoroughly enjoyed by members who were able to enjoy the fabulous facilities in the glorious weather. We also welcomed some newcomers too.

Mark Mayer wowed us at the AGM with his wonderful use of signing to complement his Chairman's report. The children (and adults) were mesmerised by our amazing magician, Colonel Custard, who entertained us all and made us laugh.



Sunday 14th July 2019

SAVE THE DATE

We will be returning to our popular venue again for our annual family day and AGM next year.

To find out more about the facilities then please look at:

www.tvap.co.uk

Thames Valley Adventure Playground, Bath Road, Taplow, Nr. Maidenhead, Berkshire, SL6 0PR