DOWN SYNDROME SOUTH AFRICA

Working to improve the lives of people with Down syndrome, other intellectual disabilities and their families.

In this issue:

08th – 10th June 2013
Annual General Meeting and National Staff meeting.

20th -21st June 2013
Down Syndrome International Annual General Meetings, London, UK

13th – 15th July 2013
International Disability Alliance – New York

16th – 19th July 2013
United Nations - Conference of State Parties, New York

It is with great pleasure that I bring to you our 2nd newsletter of the year. Please note: no newsletter was released in June since this is when the Directors annual report was presented. Available to download from the website or email the office.

HIGHLIGHTS!

DSSA has a new Chairperson: Since the last newsletter we have held general board meetings as well as our Annual General Meeting over the weekend of 8-9th May. Read on page 6 news about the AGM and our newly elected office bearers.

United Nations: I was fortunate to attend the Conference of State Parties held in New York during July. The Deputy Minister of Women, Children and People with Disabilities presented her report, which I emailed to all. Read more under United Nations on page 3.

There is simply too much to highlight here so read on... and enjoy!

Yours truly,
Vanessa dos Santos
National Executive Director

Please feel free to distribute, as they say Sharing is Caring!

Is there anything you want to add to our newsletter, if so let me know!
Email Vanessa on dssa@icon.co.za
**INTERNATIONAL NEWS**

**DOWN SYNDROME INTERNATIONAL** (DSI) held its Annual General Meeting at the London based office together with a strategic planning meeting with the board of trustees 20th - 21st June 2013.

**NEW ASSISTANT DIRECTOR** – Roxanne Scholtz (our previous Organisational Development Officer) has taken over as the new Assistant Director of DSI. This is as a result of DSI’s decision to have an office in South Africa. A big thank you to Down Syndrome South Africa (DSSA) for hosting and supporting this office. Also DSI thanks the Babli Foundation and the RamaChandran’s for financially supporting the position of Assistant Director.

**WEBSITE:** Down Syndrome International has launched its new look website. Check it out at [www.ds-int.org](http://www.ds-int.org) for international news.

**12th WORLD DOWN SYNDROME CONGRESS 2015:** The next World Down Syndrome Congress is to take place in Chennai, India in August 2015. This is only two years away so start saving. For more information log onto [http://downsyndrome.in/12th-world-down-syndrome-congress-2015](http://downsyndrome.in/12th-world-down-syndrome-congress-2015) hosted in partnership with the Down Syndrome Federation of India.

**INDELIBLE – THE FILM:** President elect of DSI and the President of the DS Federation of India Dr Rekha RamaChandran worked together with Bangalore based documentary film maker Pavitra Chalam to produce a 60 minute full length film titled Indelible, which feature the inspiring stories of seven persons with DS, giving hope to parents of children with special needs. Click on the link to read more: [http://newindianexpress.com/cities/chennai/Indelible-film-on-Down-Syndrome/2013/07/23/article1696589.ece](http://newindianexpress.com/cities/chennai/Indelible-film-on-Down-Syndrome/2013/07/23/article1696589.ece)

**IDA:** As the president of DSI I sit on the board of the International Disability Alliance. See below for an update.

**INTERNATIONAL DISABILITY ALLIANCE**

The International Disability Alliance (IDA) was established in 1999 as a network of global and, since 2007, regional disabled people’s organizations (DPOs). The aim of IDA is to promote the effective and full implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) worldwide, as well as compliance with the CRPD within the UN system, through the active and coordinated involvement of representative organizations of persons with disabilities at the national, regional and international levels.

With member organizations around the world, IDA represents the estimated one billion people worldwide living with a disability. This is the world’s largest – and most frequently overlooked – minority group. IDA with its unique composition as a network of the foremost international disability rights organizations is the most authoritative representative voice of persons with disabilities and acknowledged as such by the United Nations system both in New York and Geneva.

IDA was instrumental in establishing the International Disability Caucus (IDC), the network of global, regional and national organizations of persons with disabilities and allied NGOs, which was to become a key player in the negotiation of the CRPD.

After adopting its new statutes and internal rules, the IDA held its 1st board meeting in New York 13th - 15th July. The meeting was attended by the full IDA board comprising of the Chairpersons of its 12 member organisations. I also attended the Inclusive Education Workshop

These meetings were held ahead of the Civil society forum and the Conference of State Parties held at the United Nations (see more on next page). I would like to thank the IDA for making it possible for me representing DSI at the United Nations conference.
The Committee on the Rights of Persons with Disabilities will be meeting for its 10th session from 2nd – 13th September 2013 in which it will examine the reports of Austria, Australia and El Salvador as well as adopt lists of issues on Azerbaijan, Costa Rica and Sweden. On 10 September, the Committee will hold a public meeting with States Parties. The CRPD Committee’s public sessions will be webcast at www.treatybodywebcast.org.

For further information on the session’s programme and how to register by the deadline of 27th August, visit the Committee’s website.

6th Conference of States Parties to the CRPD

The Sixth Session of the Conference of States Parties (COSP) to the Convention on the Rights of Persons with Disabilities (CRPD) took place from 17 to 19 July 2013 at the UN Headquarters in New York. On 16 July, the day prior to the COSP, IDA coordinated the Civil Society CRPD Forum (CSF) with the support of Disabled People’s International, Disability Rights Fund, Global Partnership for Disability and Development, International Development and Disability Consortium and Rehabilitation International, and co-sponsored by UN DESA and the United Nations Member States of Australia, Bulgaria, Mexico and New Zealand. The CSF reviewed the negotiation process of the post-2015 framework and its inclusion of the rights and participation of persons with disabilities. Civil society exchanged views with key stakeholders in order to ensure a disability rights-inclusive and CRPD-driven future development agenda.

The theme of the COSP was “Ensuring adequate standard of living: empowerment and participation of persons with disabilities within the framework of the CRPD.” The Conference included thematic roundtables on economic empowerment through inclusive social protection; poverty reduction strategies; disability-inclusive development in national, regional and international processes; an informal panel community-based rehabilitation and habilitation for an inclusive society; and an interactive dialogue on the implementation of the Convention.

At the opening of the conference, IDA Chair Mr Yannis Vardakastanis, speaking on behalf of civil society and DPOs in particular, highlighted the importance of mainstreaming disability in future global development goals, noting that this issue currently represents the most important advocacy activity for the disability community worldwide. Chairperson of Disabled People’s International and IDA board member Mr Javed Abidi participated in the roundtable on economic empowerment; and Mr Nawaf Kabbara, in his role as third vice-chair of IDA, co-chaired the informal session on community-based rehabilitation with the Permanent Mission of the Republic of Bulgaria.

High Level Meeting on Disability and Development

The High-level Meeting on Disability and Development (HLMDD) will take place at UN Headquarters on 23 September 2013. The meeting is expected to adopt an outcome document, which is currently in its final phase of the negotiation process, on the realisation of the Millennium Development Goals and other internationally agreed development goals for persons with disabilities.

The draft outcome document is available on the website of the President of the General Assembly.

Related documents:

- Draft outcome document
- Draft programme for the HLMDD
(DSSA) I have been asked to participate together with our Project Manager John Dikgale in board meetings as well as a workshop on ‘Access to Justice for persons with disabilities who are victims to crime’ sponsored by OSIEA and Inclusion International. We will report on this in next newsletter.

John is also the Vice Chairperson of Inclusion Africa and attends monthly Skype board meetings.

SECRETARIAT OF THE AFRICAN DECADE FOR PERSONS WITH DISABILITIES

The Communities of Practice in Disability Advocacy for Mainstreaming (COPDAM) Programme - Influencing the African Union on Disability Inclusion Disability Mainstreaming and Advocacy Training Workshop 4th – 8th August 2013

Our Project Manager Mr John Dikgale representing the Down Syndrome African Network, attended this workshop. The COPDAM programme started on Monday the 4th August and the key note speaker was the Deputy Minister Henrietta Bogopane-Zulu from the department of Women, Children and People with Disabilities. A total of fifteen delegates from different African countries participated in the workshop.

The overall purpose of the training was to equip participants with expertise and skills to enhance their capacity to provide technical assistance and monitor the African Union and its organs in mainstreaming disability in different programmes.

During the four days the training outline focused on:


Thank you to the SADDP and the Down Syndrome Africa Network (DSAN) for the opportunity to attend the COPDAM Programme.

I have also been in negotiations with the CEO Mr AK Dube regarding a Capacity Building workshop for the DSAN to be held in the later part of the year focusing on strengthening the different DS organisations in Africa. There is a huge need to do this as many of the organisations have not only a lack of financial support or government support but also a need to empower parents and volunteers. Unfortunately at this stage don’t have sufficient funding in order to cover all the costs of the workshop, however I am still working on it.

Another project we are working on (and hope the funding will be granted) is to Advocate for the fundamental freedoms and human rights of women with disabilities from marginalized and persecuted disability groups. The organisations will be the Secretariat of the African Decade of Persons with Disabilities, Network of African Women With Disabilities, Pan African Alliance and People with Albinism, Down Syndrome South Africa and Disabled Refuges projects.

UN DESA AFRICA TOOLKIT

Implementing the Convention on the Rights of Persons with Disabilities

I attended the above-mentioned workshop and have given input into the draft toolkit regarding Down syndrome and other intellectual disabilities.

This Toolkit is intended to help governments, national human rights institutions, persons with disabilities and allies to become effective educators and advocates on the human rights of persons with disabilities to advance implementation of the CPRD. and disability and to enable them to share both their passion and their knowledge. The Toolkit’s content draws on the work of numerous UN agencies and other international organizations, providing useful illustrations and adapting content to meet the specific needs of African country stakeholders, although it can also be used by stakeholders in other regions.

Currently there are 14 modules with a possibility of additional modules being added such as employment. The UN is to come out with a document on National Legislation – it is not a duplication and will draw on existing resources. I will be attending a follow up workshop in November conducted by the Dept of Women, Children and People with Disabilities. There is just way too much information regarding this so for more info or to receive the draft modules please email me on dssa@icon.co.za
The Break the Barrier – Strengthen the Township project is in its final stages, coming to an end January 2014, so not much longer now. I will be transferring the last of the funds for the 3rd Self Help Group in your area for the participating branches.

Networking between Self Help Groups – This activity of the project has resulted in 3 provinces having the opportunity of Networking. The two branches Self Help Groups in Limpopo, namely Tzaneen and Polokwane and in the Eastern Cape, namely Amothele and Port Elizabeth have had their networking meetings during June and July. Unfortunately the North West Province Network meeting was delayed and only took place weekend 24th/25th August. Reports from these groups have been extremely positive with all saying they have enjoyed the opportunity of sharing stories. Whilst many of the stories coming from the groups have been similar, there have been some which have been unique. The group felt good to be able to share these stories with one another and some were even able to help the other groups/parents how to solve some of the issues. So it seems the aim of the networking was achieved. The groups have also asked that these sessions can take place again…now just to find the money to do so!

The ‘My Dad Takes Part in the Family’ is in the process of being finalised and the training will be conducted in the latter part of the year. We will be training fathers from the townships around being included and participating in the family and their disabled child. Please could each Self Help Group identify one father who could attend the training which will take place 23rd & 24th 2013 (Sat & Sun) in Johannesburg. These fathers must be able to go back into their groups and give feedback that will assist the other fathers.

SELF ADVOCACY TRAINING and NEW SELF ADVOCACY CHAIR AND VICE CHAIR

This training took place over a weekend and we had 33 participants from all the townships that are participating in the project. Two people from each self help group from the selected townships (of the project) one self advocate and one support person participated. Since we had enough space for more people we opened it up to others who wanted to attend as well. In total we had 30 participants from all over South Africa.

The Chairperson of the SAMSA, miss Hayley Rehbock and Vice Chairperson, Mr Ephraim Mohlokane also attended and assisted with the training. All enjoyed the weekend workshop and reported that they learned a lot and look forward to going back to their local areas and implementing what they learned with their own groups. At the end of the training the self-advocates were asked to nominate and vote in a new Chair and Vice Chairperson since Hayley’s and Ephraim’s four years terms had come to an end. Miss Thenjiwe Ndebele was voted in as the Chairperson and Mr Kagiso Nwandula Vice Chairperson. Congratulations to both of you and we look forward to having you on the National Down Syndrome South Africa as full board members. Each delegate received a certificate of participation. Congratulations to all. To view all the photos from the event check out our website www.downsyndrome.org.za under the LEV project or our Facebook page http://www.facebook.com/pages/Down-Syndrome-South-Africa/

STUDY OF LEGISLATION FOR PEOPLE WITH INTELLECTUAL DISABILITIES – See information regarding this report under DSSA news Annual General Meeting on next page.
DSSA hosted our Annual General Meeting weekend 8th–9th June together with our Annual National Staff meeting 10th June 2013. This year was an election year and a new National Chairperson was elected. Mr Thabang Chiloane was appointed to stand for the next two years 2013-2015. The Vice Chairperson Mrs Dee Khuzwayo was re-elected together with the Treasurer Mrs Klazina Hattingh and Mrs Sonia Skein as the Secretary. We also have two additional members represented on the Steering committee, which are Mrs Zimkita Metele and Mrs Lynne Rutherford. We wish them all the best in their roles! The Directors report for 2012/13 was presented together with the reports from the 14 branch/support group and outreaches. To get a copy of these reports email Gloria on dssaooffice@icon.co.za

Profile of New Chairperson Mr Thabang Chiloane

Thabang Chiloane is a Divisional Executive for Nedbank’s Group Public Affairs. Thabang fulfills the critical role of managing stakeholder relationships specifically in the public sector space. A graduate of the Argus School of Journalism, he also has Bachelor of Communications degree from the Charles Sturt University in Australia and is currently completing a Master of Business Administration degree through the Regenesys Business School in Johannesburg.

He was previously head of Group Government Relations at banking group Absa and prior to that headed up group communications at Sanlam. Between 2006 and 2008 he was in charge of communications for the deputy president of South Africa. Earlier in his career, he headed up communications for the Kwazulu-Natal Provincial Government, the National Department of Housing and the Kwazulu-Natal Department of Transport. He also spent two years at GCIS setting up BuaNews, the Government News Agency. He is the 1999 African Radio Journalist of the Year. Thabang is a keen reader, loves music and is currently working on a book about surviving a plane crash and other life challenges.

He has travelled widely and has an open mind. He loves a good constructive debate. He is a father of four, one of them Thapelo who is three years old with Down syndrome. Thabang has been the chairperson of the Tshwane Down syndrome association since 2011.

STUDY OF LEGISLATION FOR PEOPLE WITH INTELLECTUAL DISABILITIES – LEV PROJECT

During our AGM and Staff meetings I gave a presentation of the desktop study conducted by DSSA in 2012 on “Disability Related Legislation in South Africa” which formed part of the LEV project. The aim of the study is to:

- Strengthening the parents ability to lobby for their children’s rights making sure they have adequate knowledge on tools and processes that they can use to lobby for their children’s rights;
- Advocacy tools include international and national legislation, instruments and policies;
- Studies show that there is a general limited public awareness of disability related legislation and policies among parents, people with intellectual disabilities, community leaders and government officials;
- This impacts negatively on social and economic participation of people with intellectual disabilities;

The report provides a summary of key sections of South African related legislation and policies that promotes social and economic participation of people with disabilities including people with intellectual disabilities.

For a full report of the study contact Gloria on dssaooffice@icon.co.za or 0861-369-672 – Also keep a check out on the website as I will be putting the power point presentation up under the projects page.
INCLUSIVE EDUCATION PACKS
A Guide for Educators, Education Support Staff and Parents

‘Including Learners with Down Syndrome’

Thanks to the NLDTF we have been able to develop, print and train on the Inclusive Education Packs. Also thanks to the Down Syndrome Association of the United Kingdom who gave us permission to adapt the pack to a more local and South African context.

These packs will be available to order from our website www.downsyndrome.org.za from the 9th September or from Kearen Bromilow on 0861-369-672 or dssa.odo@icon.co.za however it is advisable to also attend the training and not just purchase the books alone.

Branches can purchase these packs from us now at a reduced rate. Please place your order by 9th Sept (the latest). Once these have been placed we will not be ordering again for quite a while so will NOT be carrying stock to keep for the branches.

DSSA will be conducting our first training session on the packs for our branches/support groups and outreaches from our offices based in Bruma on the weekend of 5-6th October 2013. DSSA will be covering the costs of one person (who MUST be your inclusive education contact person on your board. Please guys, we don’t want just anyone to attend just for the sake of having someone here from your branch and then that person is not able to give the training back at a local level. This person will also have to sign an agreement to attend which will be sent to you in due course)

The pack comes in 10 Units and training includes topics such as:

- Unit 1a - Introduction to Down syndrome and their specific learning styles;
- Unit 1b - Legislation and Guidance, laws, policies and guidelines, useful reading;
- Unit 2 – Effective strategies for inclusion such as creating an inclusive school, classroom planning and individual support plans and using additional adult support effectively;
- Unit 3 – Developing Language Skills, Language development in Down syndrome, Strategies to promote language, including signing, teaching reading to teach talking
- Unit 4 – Accessing the Curriculum, planning for differentiation, suggested access strategies
- Unit 5 – Reading, learning to read and getting started, recommended software
- Unit 6 – Developing Writing Skills – Fine motor development and how to develop these skills, reasons for delays, letter formation, writing phrases, alternative methods, developing sentence structure, extending writing, spelling;
- Unit 7 – Acquiring Mathematics and Numeracy Skills, developing basic numeracy, maths skills, language of maths, difficulties associated with learning maths,
- Unit 8 – Promoting Positive Behaviours and Social Skills, Behaviour, strategies, causes of inappropriate behavior, promoting social inclusion;
- Unit 9 – Successful Transitions, Starting school, moving from pre-school to primary, transition from primary to secondary and high school;
- Unit 10 – Computers as an aid to learning, computers and the curriculum, advantages, computers in school and children with Down syndrome and useful websites.

As you can see from the content these packs are jam packed with everything Educators, Education Support Persons and Parents need to know. Should anyone else be interested in joining us please contact the office for more information.
There is much need for information to be shared, and for people working in the field to have a better understanding of Down syndrome and other intellectual disabilities. It is this reason that DSSA will be conducting the following training:

New Parent Support and Basic Counseling Skills; April 2014 (date to be confirmed)
This training will concentrate on up skilling interested people in supporting and counseling new parents who have just received a positive diagnosis of Down syndrome (or similar disability). Topics covered are:

- Basic information on Intellectual disabilities;
- Background of counseling skills;
- Practical counseling skills;
- Basic attitudes and ethics;
- Dealing with grief.

What you need to know – All about Down syndrome and other intellectual disabilities, 2nd Nov
…about babies and children with Down syndrome, Intellectual disabilities, Developmental and Cognitive delays…

Basic Support and Early Intervention Strategies for babies and children with Down syndrome and similar disabilities is a programme that has especially been designed for new parents and other people who come into contact with young children with Down syndrome, Intellectual disabilities or Developmental and Cognitive delays.

The appropriate training covers topics that will ensure all participants will leave feeling empowered, confident and with a better understanding of babies and children with intellectual disabilities or developmental and cognitive delays. Don’t delay…Book today to participate.

The one-day training will consist of:

- What is Down syndrome and the medical issues to look out for;
- Other intellectual disabilities, developmental and cognitive delays;
- Basic support and what to expect;
- The importance of Early intervention;
- Development of communication;
- Social development;
- Motor development;
- Practical Early intervention strategies;
- Where to from here.

Inclusive Education - 5th & 6th October – See info on page 7

Right to Know – series on Friendships, Sexuality, Safety and Protection; 1 day (as and when needed)
Appropriate training about relationships, sexuality and protective behaviours is vital for all persons with Down syndrome and other intellectual disabilities. The programme provides information and specific programming about a wide range of issues, which affect the quality of life, relationships and safety of those with Down syndrome and intellectual disabilities. In addition, much of the material has applications for other students with and without intellectual disabilities.

Comprehensive training programme for schools, parents and carers to ensure that people with Down syndrome and other intellectual disabilities have the opportunity to develop skills and understanding from an early age.

The programme contains 3 modules – Friendships, Sexuality, and Personal safety. Each module is comprised of a series of Units, which address specific aspects of the Module theme.

Promoting and Protecting the Rights of People with Intellectual Disabilities and their Families; 1 day (as & when needed)
Advocacy and lobbying is vital not only for organisations but also for parents/family members of children with disabilities such as Down syndrome and other intellectual disabilities. This training is aimed at family members as well as those working in the field to empower them in order for them to know and understand their rights about policies and legislation and service provision in a manner that is easy to understand and follow. At the end of the training participants such as Parents of children with disabilities will be able to stand up for their child’s rights giving them access to services that they would not previously been able to access.

Target Audiences:
Parents of children with Down syndrome or other intellectual disabilities; Educators and teacher assistants/facilitators; Therapists; Students; Health care professionals; Interested persons working in the field.

Training costs:
R300.00/person/day for parent/family members. R400.00 others and professionals. This fee includes all training material, certificate, lunch and refreshments. CPD points for professionals (TBC). Interested persons please email Gloria on 0861-369-672 or dssaoffice@icon.co.za All training will take place at our offices in Bruma Johannesburg (Min 6 persons per session).

NB! Should you wish the training to take place in your area please phone or email for more information.
DSSA NEWS

NATIONAL LOTTERY DEVELOPMENT TRUST FUND

DSSA OUTREACHES

THANK YOU NLDTF, FOR YOUR SUPPORT FOR BOTH THE INCLUSIVE EDUCATION AND OUTREACH PROJECTS

As reported in our last newsletter and at our AGM our lotto funding for project 50313 effectively came to an end in June. Even more bad news is we still have not heard if our application submitted in 2012 has been accepted or not. This effects our 5 Outreaches, namely Tzaneen, Kimberley, Witbank, Potchefstroom and Bloemfontein, which we financially support through the funding, received from the NLDTF by employing an Outreach Coordinator in each of these areas as well as providing other support. I, however have managed to find some funding to continue employing these coordinators until the end of the year 2013. I am also trying to access funding through other avenues to see if we can keep these coordinators employed for a further year and beyond. These outreach coordinators have done a tremendous job with very little resources and very often using their own initiative to implement activities. They all send monthly reports to the Project Manager John Dikgale. Below is a brief report from the Project Manager John Dikgale of what the outreaches have been up to lately:

Keep up the good work guys! We at DSSA are very proud of you.

Northern Cape Outreach Group- Kimberley

As from July 2013 Ntombi Ndlovu the co-ordinator of the outreach group in Kimberley embarked on awareness campaigns by visiting more clinics in the area. These campaigns have made it possible for more parents to join the outreach group. The group has started to hold meetings on Sundays. To appreciate mothers in the group they have earmarked the 22 August 2013 to celebrate the women’s’ month. On the 24 and 25 July two parents, Betty Mohitlhi and Horatius Seekoei attended the department of Social Development consultations on disability grants and they found the consultations very productive. The Self Help Group meetings are still being held once a month on Saturdays.

Limpopo Outreach Group – Tzaneen

The outreach group held their meeting on the 15 July 2013 to discuss how to overcome challenges they face in the community. Some of the solutions they came up with are to find support to expand the food gardens and to find a donor for equipment for their bakery project. They also asked Nelly Marokane from the Polokwane Outreach Group to do art training for them. The art training session will be held on the 17 August at N’wamitwa village and 22 parents will participate. They have a challenge of sourcing art equipment.

Limpopo Outreach Group – Polokwane

The activities of the Polokwane outreach group were greatly compromised and effected due to ill health of Grace Sekhu who co-ordinated the group. Nelly Marokane and Zaza Mogale held a meeting with Grace Sekhu and they were roped in to assist with the running of the group in the interim. It was also suggested that the group need to hold a special meeting in September 2013 of all the members in the presence of officials from Down Syndrome South Africa to discuss the way forward for the outreach group.

North West Outreach Group – Mafikeng

During the month of July the Mafikeng outreach group members embarked on a Door-to-Door campaign to raise awareness about Down syndrome. They found eight children who were hidden from the community. The parents of the children were given advice about inclusion in the community and have since joined the outreach group. It was also found that most children in the villages are not attending school. Nontsikelelo Sojane attended Disability Grants consultations hosted by the department of Social Development on the 19 and 20 June 2103 in Mafikeng. She is compiling a database of children who are excluded from receiving the disability grant and those who are not attending school.
North West Outreach Group – Potchefstroom

The Potchefstroom outreach group held a meeting on the 27th July 2013 and the parents were briefed about the DSSA Annual General Meeting that took place in June. The chairperson of the group presented the NPO certificate to the committee which he motivated to work harder. They also discussed an initiative to start a crop production programme for unemployed parents in the outreach group. The chairperson decided that they must elect a new committee to assist the co-ordinator. The Networking between the self help groups in the North West Province will take place at Tshwaragang Hall in Potchefstroom on the 24th August 2013. Thirty five parents will participate in the planned networking session.

Parents in the group have been encouraged to support and participate in the Casual Day on 6th September.

Mpumalanga Outreach Group – Witbank

A young girl with Down syndrome aged fourteen was raped in Witbank by a neighbour during the month of June. The swift action of the community made it possible for the perpetrator to be arrested. The parents from the outreach group protested outside the court and these actions pressurised the magistrate to deny the perpetrator bail. The next court hearing will be on 10th September 2013. The matter was referred to Thutuzela Care Centre in Witbank who are handling the medico-legal aspects of the case to assist the young girl. On the 19th July 2013 Vodacom in Mpumalanga celebrated the Nelson Mandela Day with the Witbank outreach group. They had lunch at McDonalds and the children were given an opportunity to enjoy themselves in the play centre at the Ridge Casino. During August three parents from the outreach group, Dudu Mtshweni, Meisie Ntuli and Mirriam Masango participated in the Disability Consultations hosted by the department of Social Development in Nelspruit.

Networking with other Stakeholders about the Disability Agenda

Department of Social Development – Disability Consultation Programme

On the 19 and 20 June 2013 John Dikgale and Nontsikelelo Sojane attended the Civil Society Consultation Programme on Disability Grants organised by the Department of Social Development in Mafikeng. The purpose of the consultations was to discuss the Care Dependency Grants and Disability Grants. There were presentations focused on the Assessment Framework which dealt with the legislative framework, definition of disability, eligibility criteria, means test and trends. The Harmonised Assessment Tool was also presented and the gaps in the social assistance programme were also identified. The current process of health professionals refusing people with Down syndrome access to care dependency grants and disability grants was also discussed. The officials from the department of Social Development expressed their frustrations in implementing the Harmonised Assessment Tool as the barrier being that doctors who need to be trained about the tool and the department of Health are not assisting in the implementation of the tool.
DSSA are now for the first time National Beneficiaries of Casual Day! This is great news for us. All branches, support groups and outreaches including DSSA have taken a total of 29000 stickers, which we need to sell by the 6th September. If there is anyone out there who wants to assist us or one of our branches in your area as volunteers please make contact with Kearen Bromilow on 0891-369-672 or dssa.odo@icon.co.za

The stickers sell for R10.00 each. This year’s theme is to GO BIG, so the idea is to wear or do anything that is BIG!

**20TH OCTOBER NATIONAL DOWN SYNDROME AWARENESS DAY!**

‘IT’S ALL IN THE GENES’

20th October annually is the National Down Syndrome Awareness Day and the theme for this day is “It’s all in the Genes” since Down Syndrome is a genetic condition we ask people to wear Jeans on this day and purchase a sticker for R5.00 and if possible give an additional R5.00 (fine) for wearing the jeans. This year the 20th falls on a Sunday, which is a great day for branches, support groups and outreaches to arrange family fun days such as picnics, buddy walks…etc. Just get out there and be seen. Prior to the day talks at schools or companies can be given, which is also a way of not only raising awareness but raising much needed funds. Schools can include the talk into the Life Orientations programme. So do what you can to raise awareness! Posters and stickers available from Kearen Bromilow 0861-369-672 or dssa.odo@icon.co.za

**KEEP CALM T-Shirts.** These will be available to purchase for branches/support groups and outreaches at R55.00 ea and sell to the public at R65.00ea including VAT. They are white (excellent quality) with black print.

Place your orders ASAP with Kearen Bromilow on 0861-369-672 or dssa.odo@icon.co.za

We are also in the process of getting quotes for the same logo to be printed on mugs, baby grows and bibs and will keep you updated if we do go ahead. Also keep a check out on our website for updates, but don’t forget to REFRESH the page.

**2014 DIARIES**

We will be placing our order for the 2014 diaries so if you are interested in ordering from us do so ASAP. They are selling at R100.00 ea make wonderful gifts to give to those who support us and board members and to buy for your friends, colleagues etc. It includes information regarding Down syndrome and our awareness days. It also shows that you belong to and or support a national organization. Contact Kearen Bromilow on 0861-369-672 or email dssa.odo@icon.co.za

**LADIES BREAKFAST – CHARITY FUNDRAISING EVENT! – SAVE THE DATE 26TH OCT**

DSSA will be hosting a LADIES BREAKFAST to be held on the 26th October (Saturday). Venue to be confirmed. Tickets are sold at R180/person – includes full breakfast with Champagne, Fantastic prizes – Lucky draw and entertainment.

GET YOUR FRIENDS TOGETHER AND BOOK A TABLE

To book email Kearen Bromilow on dssa.odo@icon.co.za or 0861-369-672
WE HAVE MOVED OFFICES!

LAKESIDE TWO – 1ST FLOOR ROOM 109
3 ERNEST OPPENHEIMER STREET
BRUMA
JOHANNESBURG
011-615-2990
Mon – Thurs 8.30am – 4.00pm
Fridays 8.30am – 1.00pm

DSSA IS ON FACEBOOK AND TWITTER

Look for us on Facebook and Twitter, just type in ‘Down Syndrome South Africa’ and like us.

Updates on national as well as international issues are posted almost daily.

NB! Don’t forget to forward us the latest info and updates for your website page, such as change on names, contact details, photo etc...

Down Syndrome South Africa
Website www.downsyndrome.org.za

Website

The website is continuously being updated, however there has been a big change in the font and text, REFRESH the page to check out what is going on!

Staff matters

We have now officially employed Kearen Bromilow who has taken over the role of Organisational Development Officer. Please contact her with regards to any media, awareness, events, training, printing, etc. on dssa.odo@icon.co.za

Down Syndrome South Africa Contact Details

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