

# NEWS & VIEWS

Down Syndrome Association Malta

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# The Association

The Association promotes the interests, developments and inclusion in society of persons with Down Syndrome.

## SERVICES:

- Parental Support
- Aerobics, weekly
- Mass and Tombola, First Friday of month
- Social activities: three times yearly
- Talks and fora
- Christmas Party and Disco
- Book, audiotapes and video library
- "News & Views" magazine: yearly
- Members Newsletter

## MEMBERSHIP:

Full members:  
Annual: €2.50      Life: €25

Associate members:  
Annual: €5.00      Life: €35

## EDITORIAL CONTRIBUTIONS:

Esperjenzi, artikli u ittri mill-qarrejja għal dan il-magażin huma dejjem milqugħa.

Experiences, articles and letters from our readers to this magazine are always welcome.

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Federazzjoni Maltija tal-Organizzazzjonijiet  
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Hbieb,

Is-sena li għadha kemm spiċċat, is-sena 2011, kienet iddedikata lill-volontarjat fuq skala Ewropea. Id-defenizzjoni tan-Nazzjonijiet Uniti għall-volontarjat hija li l-ewwelnett ma jkunx hemm hlas għal dan ix-xogħol (naturalment l-ispejjeż involuti għandhom jiġu mhallsa): l-individwu jidhol għax-xogħol volontarju għax ikun irid hu u mhux għax ikun mgiegħel: ix-xogħol li jkun qed jagħmel l-individwu jrid ikun qed jibbenefika minnu haddiehor u mhux l-istess voluntier (*United Nations Volunteer Report, February 2001*). Personalment għoġbitni hafna dak li qal Ivan Scheier, "Waħda mid-defenizzjonijiet tiegħi għall-volontarjat hija li tagħmel aktar milli għandek tagħmel (*doing more than you have to*) – għax trid – f'kawża li tikkunsidra li hija ġusta".

Il-volontarjat jista' jkun formali, jiġifieri tghin mingħajr hlas permezz ta' gruppi u/jew organizzazzjonijiet jew jista' jkun informali – tagħti għajnuna mingħajr hlas fuq bażi individwali. L-Assoċjazzjoni Down Syndrome hija Assoċjazzjoni volontarja u t-tmexxija tagħha hija tmexxija volontarja. L-Għaqda tagħna tiddependi hafna mill-volontarjat u hawnhekk nixtieq nagħmel dak li ilni nagħmel għal dawn l-aħħar sitt snin kemm ilni President tal-Għaqda – inhegġeġ lilkom membri biex minn jeddkom tagħtu mill-hin tagħkom u tkunu attivi fit-tmexxija tal-Għaqda. L-Għaqda hija ahna lkoll.

Jiena nhoss li fuq bażi nazzjonali, il-volontarjat għandu jingħata aktar rispettu u importanza u allura jingħata l-ispazju tiegħu. Fejn huwa postu l-volontarjat fuq bażi nazzjonali? Postu għandu jkun kullimkien

– kull fejn jolqot dak li qed jaħdem għalih. Fl-opinjoni tiegħi l-volontarjat hawn Malta, b'mod partikolari fil-qasam tad-dizabilità, mhuwiex jingħata importanza kemm u kif suppost. Nitkellmu, ingibu fondi mill-Unjoni Ewropea u nhegġu lill-pubbliku biex jiehu sehem fid-djalogi ċivili li jkunu organizzati minn żmien għal żmien fuq *issues* fuq livell Ewropew, imma mbagħad inhallu barra lill-volontarjat fid-djalogi ċivili f'dak li jirrigwardana direttament fuq bażi nazzjonali. U dan minkejja li l-volontarjat irid li jkun involut f'diskussjonijiet li jirrigwardaw l-*issues* tagħhom.



Nittama li s-sena ddedikata lill-volontarjat tħalli l-marka tagħha u naraw bidliet. Nittama li naraw ir-riżultati pożittivi tagħha fuq bażi nazzjonali u dan billi l-volontarjat

jibda jkun dejjem mistieden biex ipoġġi madwar il-mejda mal-awtoritajiet konċernati fejn l-*issues* li jkun qiegħed jaħdem fuqhom u għalihom matul is-sena/snin ikunu qed jiġu diskussi u fejn ukoll jittieħdu d-deċiżjonijiet aħħarija fir-rigward.

L-Assoċjazzjoni tagħna taf liema huma l-bżonnijiet tal-membri tagħha u liema hu l-aħjar mod li għandhom jingħataw is-servizzi biex verament jibbenefikaw minnhom il-membri tagħha. Allura huwa sens komun li l-Assoċjazzjoni Down Syndrome għandha tkun involuta fuq dak kollu li jolqot lill-membri tagħha f'kull hin. Nittama li t-talba tal-Assoċjazzjoni tagħna ma taqax fuq widnejn torox.

Nixtieqilkom is-sena t-tajba, mimlija saħħa u risq.

# Contents

# Editorial



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Views expressed in this magazine may not necessarily be those held by the Editor or by the Down Syndrome Association.

L-artikli u l-veduti miġjuba f'dan il-magażin mhux bilfors juru l-opinjoni tal-Editur jew tal-Għaqda Down Syndrome.

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## FRONT COVER

It-tliet attivitajiet li saru b'celebrazzjoni tat-30 anniversarju.

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## Down Syndrome Association

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Dear friends,

It is with great pleasure that we bring you our 38<sup>th</sup> issue of the News & Views, 2011. This issue of our News & Views is all about you: our children with Down syndrome, our benefactors and members of this Association.

As we all (parents) know, to all intents and purposes a newborn human baby is helpless. Not only is it physically dependent on older members of the species but it also lacks the behaviour patterns necessary for living in human society.

It is within this understanding that our Association is committed to advocating ways to improve the quality of life of all persons with Down syndrome, making headway by having our children stand up and speak for themselves during conferences, seeking ways for their rights for employment opportunities, promoting the fact that they have the right to live with independence, dignity and security as valued adults and full citizens in our society.

Therefore, by knowing and understanding your rights as parents and family members of persons with Down syndrome, our Association welcomes you to join in the ongoing process of adopting a common, consistent and unified approach towards empowerment and uplifting of our already provided services and support to the benefit of our children.



We will all accomplish our members' dreams when we continue to participate fully in whatever activity (fund raising), outings, Down syndrome conferences and networking.

I would like to take this opportunity to thank those who have supported us financially and /or in any other way. Without your support we would not have been able to achieve what we have.

All the best while wishing all of you a very happy festive season,

Regards

**Mr. Patrick Umanah**

M.A, B.ED (HONS), B.A (HONS), B.A.

# Il-Jum Dinji tad-Down Syndrome

Peress li din is-sena 2011 l-Assoċjazzjoni Down Syndrome kienet qiegħda tfakkar it-30 anniversarju mit-twaqqif tagħha, il-Kumitat hass il-bżonn li anke l-Jum Dinji tad-Down Syndrome jigi mfakkar fuq livell oghla minn tas-snin l-oħra.

Fil-fatt, f'dan il-jum tal-21 ta' Marzu, 2011 l-Assoċjazzjoni tagħna, permezz tal-President, tal-Viċi President, tas-Segretarju u tal-PRO, iltaqgħet mal-Onor Prim Ministru f'Kastilja u miegħu ddiskutiet u ġibdet l-attenzjoni għal diversi punti li jolqtu lill-membri u lill-Għaqda tagħna. Huwa ġie ppreżentat bil-Memorandum "Kwalità ta' Hajja għall-Persuni Down Syndrome".

Eżattament wara din il-laqgħa, onorawna bil-preżenza tagħhom fiċ-Ċentru tagħna l-Onor Dr Joseph Muscat MP, l-Onor Dr Justyne Caruana MP, l-Onor Dr Stephen Spiteri, is-Sur Michael Briguglio u Ms Claire Azzopardi Lane. Wara li l-President tal-Għaqda qrat il-Memorandum, li kopja tiegħu ingħatat lill-Onorevoli u lis-Sinjuri hawn fuq imsemmija, kull wieħed u waħda minnhom taw il-kontribut tagħhom fir-rigward. Din il-laqgħa fissret hafna għalina u kienet importanti hafna għalina li naħdmu bla heda fuq bażi volontarja biex intejbu l-hajja tal-persuni Down syndrome. Kienet okkażjoni fejn, għall-ewwel darba madwar l-istess mejda, l-Assoċjazzjoni Down Syndrome setgħet tidduskuti u tisma' dak li għandhom xi jgħidu persuni politiċi dwar dak li jolqot lill-persuni Down syndrome. Dan li ġej huwa dak li ġie ppreżentat:-

**Lill- Onor. Prim Ministru Dr Laurence Gonzi**  
**Onor. Ministru Dolores Cristina**  
Ministru għall-Edukazzjoni, Famija u Impjieg  
**Onor. Dr Joseph Muscat MP**  
Kap tal-Oppożizzjoni  
**Onor. Dr Justyne Caruana MP**  
Kelliema tal-Partit Laburista għall-Familja u Ugwaljanza  
**Sur Michael Briguglio**  
Chairperson, Alternattiva Demokratika  
**Ms Claire Azzopardi Lane**  
Kelliema Alternattiva Demokratika għad-Diżabilità

**Mill- Assoċjazzjoni Down Syndrome**

**Suġġett: Kwalità ta' Hajja għall-Persuni Down syndrome**

**Data: 21 ta' Marzu, 2011**

Illum, l-Assoċjazzjoni Down Syndrome qiegħda tfakkar il-Jum Dinji tad-Down Syndrome. L-ewwel darba li ġie mfakkar dan il-jum dinji kien fil-21 ta' Marzu 2006 f'Singapore. Il-ġurnata u x-xahar intgħażlu hekk għax il-kundizzjoni Down Syndrome hija assoċjata mat-tliet (3) koppji tal-kromozoma 21 (trisomy 21). Għalhekk hadu l-21 bħala l-ġurnata u t-tielet xahar tas-sena.

Għas-sitt sena konsekuttiva, l-Assoċjazzjoni Down Syndrome qiegħda tingħaqad ma' Assoċjazzjonijiet oħra madwar id-dinja biex inqajmu kuxjenza għall-persuni li għandhom Down Syndrome.

Il-kundizzjoni Down Syndrome skopriha Dr John Langdon Down, tabib Inġliż u li għaliha ssemmiet din il-kundizzjoni. Fost pariri li għadda lill-istudenti tiegħu, tissemma hafna "Aim High Enough". Illum, b'dan il-motto quddiem għajnejha, l-Assoċjazzjoni tagħna qiegħda tiegħu din l-opportunità biex tgħinkom tghinu lil uliedna biex ikunu jistgħu, huma wkoll, jimmiraw fil-għoli.



Mix-xellug Antoine Gauci (Segretarju), Marthese Mugliette (President), l-Onor. Prim Ministru Dr L. Gonzi, Charles Vassallo (Viċi President), Pio Fenech (PRO)

Ir-rappreżentanti tal-Assoċjazzjoni Down Syndrome waqt il-laqgħa mal-Onor. Prim Ministru



Mix-xellug l-Onor. Dr Justyne Caruana, l-Onor. Dr Joseph Muscat, is-Sinjura Marthese Mugliette (President), l-Onor. Dr Stephen Spiteri, is-Sur Michael Briguglio, Ms Claire Azzopardi Lane

Il-membri u l-Kumitat li kienu preżenti għal-laqgħa mal-politiċi



# L-Għoti tal-Għajnuna Finanzjarja mill-Fondi tal-iStrina lill-Benefiċjarji tal-Programm REACH

Dan jista' jkun possibbli kemm-il darba:

1. saħħithom tibqa' tiġi segwita kif u kemm suppost anke wara l-erbatax-il sena tagħhom meta ma jibqgħux jaqgħu taħt id-Dipartiment tal-Pedjatrija.
2. il-kurrikulu edukattiv ikun verament iwassalhom għall-“iżvilupp sħiħ tagħhom inkluż il-hila għax-xogħol” (*I-Att dwar l-Edukazzjoni*).
3. uliedna, bħal shabhom l-oħra, ikunu jistgħu jibbenefikaw huma wkoll minn edukazzjoni adulta professjonali li tkun addattata għall-ħtiġijiet u l-abilitajiet tagħhom. Huma għandhom ukoll ikunu nkluzi fil-pjanijiet tal-*Life Long Learning* – edukazzjoni tul il-ħajja – bla skossi, bla waqfien u bi professjonalità u rispett li tixraqilhom. Sal-lum, minkejja li tlabna għall-għajnuna fir-rigward lid-Direttorat tal-*Life Long Learning*, ir-risposta kienet li preżentament mhumiex f'pożizzjoni li jagħtuna din l-għajnuna.
4. tingħata l-attenzjoni mmedjata u meħtieġa biex ikun hemm skema tas-*Supported Employment* professjonali. Minħabba li din il-professjonalità ma teżistix, għandna membri li ilhom madwar 8 snin fuq ir-regjistru tal-ETC minkejja li huma kapaċi jagħtu sehemhom fid-dinja tax-xogħol.
5. **I-Assoċjazzjoni Down Syndrome** tingħata għajnuna finanzjarja biex fost oħrajn tkun hi stess li toffri servizz ta' *self advocacy* lill-membri tagħha.
6. ikun hemm skema fejn persuni li għandhom *Down Syndrome* ikunu jistgħu jibbenefikaw minn għajnuna ta' *personal assistants* professjonali bl-inqas piż finanzjarju possibbli għall-istess persuna *Down Syndrome*.
7. il-pensjoni li wliedna jirċievu kull xahar tkun tali li jistgħu jgħixu ħajja indipendenti.
8. niffacilitaw il-ħajja tal-persuni *Down Syndrome* biex ikunu jistgħu jgħixu ħajja indipendenti, anke minn meta l-ġenituri tagħhom ikunu għadhom ħajjin. Dan jista' jseħh biss jekk naħsbu u nippjanaw għal djar żgħar fil-komunità speċifikament biex jilqgħu fihom persuni b'nuqqas intellettuali mhux sever u nagħtuhom dik l-għajnuna li għandhom bżonn (f'dan il-każ l-għajnuna hija minima) biex jgħixu ħajja indipendenti ma' shabhom. L-impjieg jgħin għal aktar indipendenza.
9. **I-Assoċjazzjoni Down Syndrome** tingħata l-għajnuna li ilha titlob biex tohloq ambjent ta' rikreazzjoni għall-persuni *Down Syndrome*.
10. tagħtu kas dak li aħna persuni *Down Syndrome* qed inwasslulkom permezz tal-Għaqda tagħna, temmnu fina u tgħinuna nilhqu l-miri tagħna.

Filwaqt li **I-Assoċjazzjoni Down Syndrome** tiringrazzjakom għall-interess tagħkom f'dak li jirrigwarda lill-membri tagħha, tittama li tkun involuta f'diskussjonijiet u f'deċiżjonijiet li jittiehdu fir-rigward għall-benefiċċju tagħhom.

Intom tistgħu u għandkom tagħmlu d-differenza fil-ħajja tal-persuni *Down Syndrome*. Grazie.

Marthese Mugliette  
President

Din is-sena, dawk il-membri li kienu rreġistrati fil-programm REACH – li kien programm addattat għaż-żgħażaġh membri tagħna li kienu spiċċaw mis-sistema edukattiva u li f'dak iż-żmien ma kienx hawn post addattat għalihom fejn setgħu jkomplu jitgħallmu u jedukaw ruħhom kif u kemm suppost - hađu lura s-sussidju dovut lilhom mill-flus mitluba u mogħtija lill-Assoċjazzjoni tagħna mill-iStrina. Is-sussidju ngħata lil kull min ibbenefika mill-programm REACH u s-somma nhadmet skont kemm wieħed kien ilu fil-programm. B'hekk ġie aċċertat li kulhadd ġie mgħejjun.

Sfortunatament, għal raġunijiet li l-Għaqda ma kelliex kontroll fuqhom, dan il-programm kellu jieqaf. Minkejja li ilna ħafna nagħmlu kuntatti u l-isforzi tagħna kollha biex programm simili jerga' jibda għaliex għad għandna membri li għandhom bżonn u jixtiequh, s'issa għad ma rnexxilniex nerġgħu nagħmluh reali. L-Għaqda ma tiflaħx

iġġorr l-ispiza ta' programm simili IMMA ż-żgħażaġh tagħna għandhom dritt ikomplu bit-tagħlim tagħhom. Fl-opinjoni tagħna, l-iStat għandu jkun minn ta' quddiem biex jgħin anke lil dawn iż-żgħażaġh, uliedna membri tal-Assoċjazzjoni Down Syndrome, biex jibbenefikaw mill-programmi tal-*Life Long Learning* bħal kull ċittadin Malti ieħor li għandu din il-possibilità. Uliedna għandhom l-istess drittijiet u bżonnijiet bħal haddieħor u allura fil-pjanijiet tat-tagħlim għal kull età, speċjalment fil-programmi għal Tagħlim Tul il-ħajja, il-bżonnijiet tal-persuni Down syndrome għandhom jiġu kkunsidrati biex b'hekk ikun jista' jinholoq programm professjonali addattat għal ħtiġijiet speċifiċi tagħhom – programm bħalma kien ir-REACH u bħalma l-Assoċjazzjoni ilha ħafna taħdem biex programm simili jerga' jsir reali.

Marthese Mugliette  
President



Fuq quddiem mix-xellug: Francesco Galea, Peter Fenech, Joseph Vassallo  
Fuq wara mix-xellug: James Gauci, Mark Zammit Cutajar, Jean Paul Fenech, Shaun Baldacchino

# Hearing impairment in Children who have Down Syndrome

Children who have Down Syndrome tend to have a significantly higher incidence of hearing problems than other groups. Worldwide surveys suggest that as many as 70 - 80% of people with Down Syndrome will have some form of hearing problem.

This article will provide parents with essential information to enable them to understand the importance of early detection, diagnosis and management in children with a hearing loss. It will also give basic information on the different causes and types of hearing loss common to children with Down Syndrome.

It is absolutely necessary to deal with this in its earliest stages as all children require a good level of hearing to acquire language through listening to what is being said by those around them.

For most Otolaryngologists and Audiologists addressing the hearing problem in children with Down Syndrome is amongst the most challenging but rewarding aspects of their practice as it is not always easy to get the required reactions and cooperation from these children.

## Hearing

I will very briefly outline the normal function of the ear and how it works. Sound, which is created by pressure waves travelling in air, arrives at the Pinna which directs the sound into the external auditory canal. This causes the ear drum to vibrate which in turn moves the three small bones found in the middle ear. Here the pressure is kept equal to the ambient pressure in the outer ear thanks to the Eustachian Tube which links the middle ear to the nose. The small bones channel the energy created by these vibrations on to the oval window which is a small membrane separating the middle ear from the inner ear. In the inner ear the movement of the oval window creates a wave which travels along the cochlea till it arrives at its frequency specific region. Here hair cells are stimulated causing a nerve impulse to travel to the brain via the auditory nerve where sound is perceived. Anything which interferes with any stage of this transfer of sound will affect hearing.

Children with Down Syndrome have craniofacial and anatomical characteristics which contribute to hearing difficulty by increasing the incidence

of nasal blockage and discharge, obstructive sleep apnea and mouth breathing.

Enlargement of the tonsils and adenoids may also block the upper airway leading to Eustachian tube Dysfunction which is one of the commonest causes of a hearing loss due to the fact that these ventilation tubes are narrower and smaller. If the Eustachian tubes are blocked, fluid can accumulate behind the ear drum. This is known as Otitis Media with effusion (OME) or Glue Ears. OME can cause a conductive hearing loss which can be treated using pharmaceuticals prescribed by your Medical General Practitioner or Otolaryngologist. If there is no improvement, then a minor surgical intervention may be required to remove the fluid from the middle ear and the use of small tubes known as grommets may be used to ventilate the ear. Sometimes OME can become chronic and therefore to avoid scarring of the ear drum by repeated surgery, hearing aids can be used as a temporary measure until the fluid drains naturally and hearing is restored. In cases where an infection worsens as a result of continuous use of conventional hearing instruments, bone conduction or bone anchored hearing devices are used. These instruments leave the canal unoccluded and help to ventilate the ear canal whilst allowing the child to hear, as sound is delivered directly to the cochlea by bypassing the outer and middle ear. Bone anchored hearing aids require a small surgical procedure where a small abutment is screwed into the mastoid bone so that the hearing device easily clips on.

The external auditory meatus or ear canal can get very narrow in children with Down Syndrome causing a build-up of cerumen or ear wax. This can also cause a conductive hearing loss but it can be solved by having the wax removed by medical personnel. The use of cotton buds is not recommended as these will push the wax further towards the ear drum making its removal more difficult.

A Sensory Neural Hearing Loss occurs when the cochlea or acoustic nerve gets damaged. There is evidence which shows that this type of hearing loss can increase with time and therefore will require continuous monitoring. Hearing aids are normally used to help deal with this type of

hearing loss, and thanks to the advance and innovation in technology it is possible to fit children very accurately and offer a good level of comfort and good speech understanding. In cases where hearing loss is profound Cochlear Implants may be considered.

A mixed loss can occur when apart from having a sensory neural hearing loss a child may also have a build-up of wax, OME or any other problem with the middle ear that will cause a conductive problem.

## Diagnosis

It is very important that these children are diagnosed as soon as possible. Normally the child is seen by an ENT Specialist to make sure that there is no wax or any obvious problem which is causing the hearing loss.

Following an ENT examination the child is referred to the Audiology Unit for a series of tests. The following tests can be used to diagnose a hearing loss.

Otoacoustic Emissions – This test is an objective test which helps to determine if the cochlea is functioning. It involves the placement of a small probe in the ear canal of the child and a series of tones are produced. This does not cause any pain or discomfort and is in fact a standard test used in neonatal screening programmes across the world but the child needs to remain still and quiet which is not very always easy unless the child is asleep. The result clearly shows a “Pass” if normal function is detected or a “Refer” if there is something wrong. One must not be too alarmed if a “Refer” is obtained during the first try as this can easily occur if the child has OME, a small ear canal or a build-up of wax, therefore further investigations are needed.

Tympanometry is a test for Middle Ear function. This test helps to confirm problems like Eustachian Tube Dysfunction, Otitis Media, Perforation and other middle ear conditions. This works by inserting a probe in the outer ear canal which changes the pressure to check the impedance of the middle ear system. A small sound is emitted from the same probe which bounces off the eardrum and is picked up by a microphone also found in this probe.

The reflection of sound helps to plot a graph of pressure against compliance. The shape of the graphs is related to the different conditions.

Audiometry is a test which helps to determine hearing thresholds across different frequencies which make up speech sound. This needs to be adapted according to the age of the child as it is a subjective test and requires a certain level of cooperation and concentration. Testing can be done by using Visual Reinforcement where the child is conditioned to respond to a sound by using a visual stimulus. Older children may be conditioned to do an activity associated with a sound presented, for example, stacking a block on another, one at a time, with each tone presented. A cooperative child may be requested to press a button when he/she hears a sound. This test will clearly identify most hearing problems and will give an accurate hearing level. It will also help with the accurate fitting of a hearing aid.

## Auditory Brainstem Response Audiometry (ABRA) & Auditory Steady State Response (ASSR).

These tests are used if results cannot be obtained by using previously mentioned methods. They can take from 30 minutes to 1 hour and the child needs to remain as still as possible which can prove to be very difficult. Normally sedation may be used to allow them to be done properly and accurately. An Electrode is attached behind each ear and another two to the child's forehead. Sounds are then presented via headphones or insert earphones. The electrodes record the passage of the sound which becomes electrical stimulus from the cochlea to the brain. Both techniques help to determine different hearing conditions as well as to detect hearing threshold.

Hopefully, this information will enable parents of children with Down Syndrome to be more aware of the need of detecting any hearing problems as early as possible, targeting the problem immediately and to feel confident that these problems can be addressed with the support of ENT specialists and audiologists.

**Andrew Sciberras MSc. Aud Sci (Lond)  
Audiologist**

# L-Indirizz mill-President għall-Konferenza ta' Malta

Onorevoli Dr Coleiro Preca, Dr Micallef, Dr Marder, Profs Attard Montalto, Dr Borg, Dr England, shabi fil-Kumitat, Sinjuri nselmilkom.

Għan-nom tal-Assoċjazzjoni *Down Syndrome*, li hija Għaqda volontarja mhux governattiva, nilqagħkom hawn magħna biex permezz ta' din il-konferenza nfakkru t-30 Anniversarju mit-twaqqif tal-Assoċjazzjoni tagħna. L-Assoċjazzjoni għandha l-istorja tagħha u hekk, illum, 30 sena wara, grazzi għall-hidma tal-Kumitat u grazzi wkoll għall-membri kollha msieħba magħna, stajna nkunu hawn illum biex insiru nafu aktar dwar il-persuni *Down Syndrome* – eżattament dwar saħħet il-persuni *Down Syndrome*.

Għaliex għal dan l-anniversarju għażilna din it-tema – *'Health and Persons who have Down Syndrome'*? Fost oħrajn għażilna din it-tema għaliex aħna naraw il-persuna *Down Syndrome*, lil uliedna, bhala persuna holistika. Huma diversi *l-issues* li jagħmlu lill-persuna shiħa, fosthom *is-saħħa*. Forsi koll kemm aħna niehdu din *l-issue for granted* imma l-fatt hu li għal dawn l-aħħar hames snin, l-Assoċjazzjoni tagħna ilha taħdem bla heda biex saħħet uliedna li għandhom *Down Syndrome* tibqa' tiġi mmoniterjata anke wara l-14-il sena.

Imxejna hafna 'l quddiem u jeżistu s-servizz fil-qasam tas-saħħa għal dawk ta' taħt l-14-il sena, imma s-sistema ta' moniteragg' kontinwu għal wara l-14-il sena ma teżistix u dan minkejja l-pressjoni li ilha tagħmel l-Għaqda tagħna għal dawn l-aħħar snin. Ma jfissirx li kollox huwa dak li nixtiequ u li suppost hu meta uliedna għadhom taħt id-Dipartiment tal-Pedjatrija, però l-fatt li wara dan il-perjodu ta' moniteragg' fil-pedjatrija m'hemm assolutament xejn għal dawn l-istess tfal meta joqorbu għall-età adoloxxenti, hija inaċċettabbli u tat-thassib.

Forsi s-saħħa ta' wliedna fl-adoloxxenza u meta jikbru aktar mhijjex daqshekk importanti? Mhuwix sens komun li aħna l-ġenituri se nibqgħu u rridu nagħtu każ ta' saħħet uliedna anke meta dawn jaqbzu l-14-il sena? Nieħu l-opportunità u nappella lir-rappreżentanti tal-Onor. Ministru tas-Saħħa li huma preżenti hawn biex iwasslu dan il-bżonn urġenti għall-attenzjoni tal-Ministru. Aħna nafu li hemm min huwa interessat jieħu hsieb il-moniteragg' ta' saħħet uliedna wara l-14-il sena imma għal xi

raġuni din l-istess persuna qiegħda tinzamm lura milli tibda twettaq dan il-bżonn urġenti ma' wliedna. Nemmen li se johroġ ġid kbir minn din il-konferenza, l-akbar waħda nittama li din il-konferenza tkun l-imbuttatura biex illum qabel għada jibda s-servizz ta' moniteragg' tas-saħħa tal-persuni *Down Syndrome* wara l-14-il sena fuq bażi regolari, dejjem skont il-htieġa individwali tal-persuna konċernata.

Aħna nemmnu li t-twaqqif ta' servizz fis-saħħa għall-persuni adoloxxenti u adulti *Down Syndrome* jgħin biex minn kmieni jinqabdu l-problemi ta' saħħa. Huwa fatt li jiswa ferm anqas flus biex timmoniterja u tipprevedi problemi ta' saħħa milli biex tfejjaq.

Konvinta li illum, wara li tispiċċa din il-konferenza, koll kemm aħna se nohroġu aktar għorrief fuq is-saħħa ta' wliedna milli dhalna. U huwa importanti hafna li aħna lkoll, li b'xi mod jew ieħor għandna kuntatt dirett u relazzjoni diretta ma' persuni *Down Syndrome*, ninformaw rwieħna fuq dan is-suġġett. Qatt ma huwa tard biex titgħallem u qatt ma taf kollox.

Kulhadd huwa uniku u ma jfissirx li għax persuna għandha *Down Syndrome* allura jrid ikollha l-istess problemi bhala haddieħor jew inkella li l-istess problema se toqot lil kulhadd bl-istess mod. Imma li huwa żgur huwa li rridu nibzgu għal saħħitna u rridu niehdu hsieb saħħitna.

Nagħlaq billi nikkwota dak li kien jgħid Dr John Langdon Down, tabib Inġliż li skopra l-kundizzjoni *Down Syndrome* u li għaliha ssemmiet din il-kundizzjoni.

Fost pariri li għadda lill-istudenti tiegħu, tissema hafna **"Aim High Enough"**. B'dan il-motto quddiem għajnejha, l-Assoċjazzjoni tagħna qiegħda tieħu din l-opportunità biex twassal messaġġ – aghmluha faċli biex uliedna jkunu jistgħu, huma wkoll, jimmiraw fil-gholi. Dan ikunu jistgħu jagħmluh biss kemm-il darba nedukawhom u fuq kollox kemm-il darba nżommuhom b'saħħithom.

Grazzi

**Marthese Mugliette**  
**President**  
**Down Syndrome Association**

# Carol Singing

Din is-sena li għadha kemm għaddiet, is-sena 2011, l-Assoċjazzjoni *Down Syndrome* għalqet 30 sena mit-twaqqif tagħha. Dan ifisser li l-Assoċjazzjoni ilha 30 sena shaħ tiġbor fi hdanha ġenituri ta' persuni *Down Syndrome* biex flimkien, bis-saħħa tas-sbuħija tagħhom fl-Assoċjazzjoni, l-Assoċjazzjoni setgħet tqajjem kuxjenza dwar il-kundizzjoni *Down Syndrome* kif ukoll dwar dak kollu li jolqot lill-persuni *Down Syndrome*.

Ma nistax ma nieħux din l-opportunità tat-30 Anniversarju biex pubblikament, permezz ta' dan il-magazintagħna u permezz ta' paġna speċifikament allokata għal dan il-għan, niringrazzja lis-Sinjuri Mary Runza u Jessica Curmi li volontarjament jieħdu hsieb grupp ta' *carol singers* biex fiż-żmien tal-Milied, bil-mużika u l-kant tagħhom, imorru jferrħu lill-pubbliku ġenerali f'postijiet differenti. Dan kollu jagħmluh biex jgħbru flus għall-Assoċjazzjoni *Down Syndrome*. Sfortunatament, minhabba l-limitazzjonijiet tagħna kemm finanzjarji kif ukoll ta' *personnel*, l-Assoċjazzjoni tagħna li hija mmexxija mill-volontarjat, mhijjex f'pożizzjoni li tagħmel attivitajiet ta' *fundraising* fuq bażi regolari.

Nistgħu ngħidu li l-*carol singing* li jsir minn dan il-grupp hija l-unika mezz annwali ta' *fundraising* li tagħmel l-Għaqda. Hawnhekk ċertament ma nistax ma nsemmix lil dawk kollha li jagħmlu parti minn dan il-grupp ta' *carol singing* immexxi mis-Sinjuri Mary Runza u Jessica Curmi. Kull wieħed u kull waħda minn dan il-grupp qed jagħmel u jagħti hafna lill-Għaqda tagħna. Li kieku ma kinux dawn it-tfal, kieku l-grupp ma kienx jeżisti. Grazzi mill-qalb tmur lil kull min hu involut f'dan u ma dan il-grupp, inkluzi l-ġenituri. Grazzi talli qegħdin tghinu lill-Assoċjazzjoni tagħna żżomm fuq saqajha għax minkejja kollox, il-fondi huma neċessarji biex l-Għaqda tibqa' tiffunzjona.

Il-ġbir li sar matul il-*carol singing fl-2010* ġie ppreżentat lill-Għaqda waqt quddies organizzata mit-tmexxija tal-istess grupp ta' *carol singers*. Dan il-grupp ha hsieb il-kant għal waqt il-quddies. Din il-quddies saret nhar il-Hadd 20 ta' Frar 2011 fil-Knisja tan-Nazzarenu, Sliema fl-11.30am.

Barra minn hekk, dan il-grupp ha hsieb ukoll il-kant għal waqt il-quddies li saret il-Hadd 20 ta' Marzu, 2011 bhala parti mill-attivitajiet tal-Jum Dinji tad-*Down Syndrome*. Dan il-jum huwa mfakkar mad-



Il-grupp tat-tfal, immexxija mis-Sinjuri Mary Runza u Jessica Curmi, waqt il-quddies li saret fil-Knisja tan-Nazzarenu, Sliema



Il-grupp tat-tfal li, taħt id-direzzjoni tas-Sinjuri Mary Runza u Jessica Curmi, waqt il-quddies li saret bhala tifkira tal-Jum Dinji tad-*Down Syndrome* fil-Knisja ta' Santa Rita, il-Belt Valletta

dinja kollha fil-21 ta' Marzu. Din il-quddies li ġiet iċċelebrata lejlet dan il-jum dinji, saret fil-Knisja ta' Santa Rita, il-Belt Valletta fl-10.45am.

**Marthese Mugliette**  
**President**

# 30 Anniversarju 1981-2011

F'din is-sena 2011, l-Assoċjazzjoni Down Syndrome fakkret it-30 sena anniversarju mit-twaqqif tagħha. Il-Kumitat immexxi minni, li huwa magħmul mis-Sinjuri Antoine Gauci (Segretarju Onorarju), Patrick Umanah (Teżorier), Charles Vassallo (Vici President), Pio Fenech (PRO) u Joe Borg Bonello, Helen Mifsud, Marija Laura Mifsud, Anthony Wetz (membri) iddecieda li kif sar f'ames snin ilu, anke dan l-anniversarju għandu jiġi mfakkar fuq skala nazzjonali.

Saret hidma kbira u intensiva biex stajna nippjanaw, norganizzaw u niehdu r-riżultati sbieħ li hadna minn dawn l-attivitajiet. Il-

valur tar-riżultat huwa kbir immens meta tqis li kulma aħna qeghdin nagħmlu fi hndan u għall-Għaqda tagħna, qieghed isir fuq bażi volontarja. Mhijiex daqshekk faċli illum il-ġurnata li ssib min, b'dedikazzjoni, ikun lest li jagħti mill-hin tiegħu għall-volontarjat. L-Għaqda tagħna għadha tiftaħar li għandha membri tagħha li huma lesti li jgħinuha volontarjament biex tkompli ssemma' lehinha.

L-Għaqda semmiet lehinha billi organizzat żewġ konferenzi – waħda f'Malta u oħra f'Għawdex. L-ewwel konferenza saret f'Malta fid-29 t'Ottubru, 2011 bit-tema



Is-Sinjura Marthese Mugliette, President

L-Onor. Giovanna Debono, Ministru għal Għawdex

L-Onor. Dr Justyne Caruana MP

Dr Isabella Borg

Dr Jean Paul Grech

Dr Elena Tanti-Burlo

Għawdex

Malta



L-Onor. Dr Peter Micallef

L-Onor. Dr Mary Louise Coleiro Preca MP

Is-Sinjura Marthese Mugliette, President

Dr Liz Marder

Profs. Simon Attard Montalto



Mix-xellug: L-Onor. Dr Mary Louise Coleiro Preca MP, is-Sinjura Marthese Mugliette (President), L-Onor. Dr Peter Micallef, Dr Kathleen England, Dr Jimmy Farrugia u whud mill-pubbliku prezenti għall-konferenza ġewwa Malta.



Mix-xellug: L-Onor. Ministru għal Għawdex Giovanna Debono, is-Sinjura Marthese Mugliette (President), L-Onor. Dr Justyne Caruana MP u whud mill-pubbliku prezenti għall-konferenza f'Għawdex.

'Health and Persons who have Down Syndrome'. Stedinna lil Dr Liz Marder mill-Ingilterra li kontinwament, flimkien ma' shabha tobbha oħra, taħdem fil-qasam tas-saħħa ma' persuni Down Syndrome. Hija tatna informazzjoni utli hafna dwar is-saħħa tal-persuni Down Syndrome matul ħajjithom kollha. L-indirizz ta' Profs Simon Attard Montalto tana stampa tas-sitwazzjoni f'Malta fir-rigward u wkoll, bħal Dr Marder, enfasizza l-htieġa li jkun hemm moniteragg tas-saħħa tal-persuni Down syndrome meta dawn isiru żgħażaġh u adulti.

Fil-5 ta' Novembru, 2011 l-Għaqda Down Syndrome marret Għawdex u permezz tattieni konferenza tagħha nformat lil dawk prezenti dwar 'Dak li Jolqot lill-Persuni Down Syndrome'. It-temi li ġew indirizzati kienubarji. Dr Isabella Borg, Chief Advisor tal-Għaqda tagħna kkoncentrat dwar is-'Saħħa tal-Persuni li Għandhom Down Syndrome', Dr Elena Tanti-Burlo, li ssostitwixxiet lil Dr A. Azzopardi li ma setax jattendi, tkellmet dwar 'L-Għerug ta' Soċjetà Inklussiva' u r-riżultati pożittivi ta' soċjetà simili u Dr Jean Paul Grech ta informazzjoni dettaljata dwar kif u x'għandna nqisu meta aħna l-ġenituri niġu biex nqassmu l-ġid tagħna lil uliedna, inkluzi wild Down syndrome. Dan kollu skont il-liġijiet prezenti tal-pajjiż.

Iż-żewġ konferenzi kellhom attendenza sabiħa ferm. Għan-nom tal-Għaqda nixtieq pubblikament u speċjalment permezz ta' dan il-magazine tagħna News & Views niringrazzja lill-Onor Ministru Dr Joe Cassar, Ministru tas-Saħħa, li minkejja li ma setax jattendi bagħat lir-rappreżentanti tiegħu lill-Onor Dr Peter Micallef, Assistent Parlamentari, li għamel l-indirizz u lil Dr Kathleen England, lill-Onor Ministru Giovanna Debono, Ministru għal Għawdex, lill-Onor Dr Mary Louise Coleiro Preca MP, Kelliema Ewlenija tal-Oppożizzjoni fuq is-Saħħa, lill-Onor Justyne Caruana, Kelliema tal-Oppożizzjoni għall-Familjau Ugwaljanza, lil Dr Liz Marder, lil Profs Simon Attard Montalto, lil Dr Isabella Borg, lil Dr Jean Paul Grech u lil Dr Elena Tanti-Burlo għall-partecipazzjoni diretta li kellhom fil-konferenzi. Grazzi wkoll lis-Sur John L Peel li mexxa l-konferenza f'Għawdex, lis-Sur Anthony Borg, Kap tas-Segretarjat fil-Ministeru għal Għawdex. lill-Kumitat u lill-membri tal-Assoċjazzjoni Down Syndrome, lill-professjonisti u lill-pubbliku ġenerali li wrew interess u attendew għal dawn il-konferenzi. **Grazzi mill-qalb talli għamilu dawn il-konferenzi suċċess.**

Marthese Mugliette  
President



# Memorable Moments with Sheffield United FC

## Sheffield United FC Makes a Difference...

The Down Syndrome Association was very surprised when in July 2011 we received a communication from Mr Dave McCarthy, Managing Director of Sheffield United FC showing their interest to hold an event with our members when they were to be here in Malta later on in the same month.

This was the first time ever that our Association was asked to be involved with such a great famous football club. Infact this was the first time ever that our members who have Down syndrome were being given such a golden opportunity.



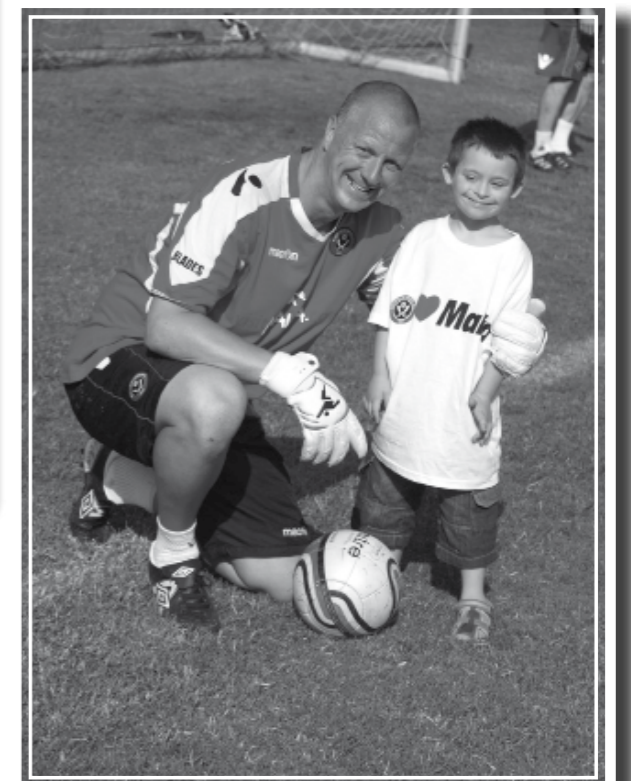
▲  
*Mr. Dave McCarthy, Managing Director Sheffield United FC presenting signed T-shirt to Ms Marthese Mugliette, President*



▲  
*Ms Marthese Mugliette President, presenting plaque to Dave McCarthy, Managing Director, Sheffield United FC*



▲  
*The plaque done and donated to us by Mr Louis Galea*



▲  
*Ms Carley Barnes*



▲  
*Mr Danny Wilson, Manager, Sheffield United FC and Ms Marthese Mugliette, President*

This opportunity came around in the same year that the Association was celebrating its 30<sup>th</sup> anniversary. We wanted to make this memorable event happen for the sole benefit of our members. It was a real big success!

# Ringrazzjamenti Speċjali f'din is-sena Speċjali

Thanks to the Manager and the Managing Director, our young members joined the Sheffield United footballers at Ta' Qali football ground. The footballers were wonderful with our members. Happiness was felt and could be seen on the faces of all participants – both our members and the Sheffield United footballers. The footballers were great with our members and our members showed them their appreciation by actively taking part and doing their very best to be successful in what they were doing.

This event will be always remembered by the Down Syndrome Association. The Association was kindly donated the Sheffield

United t-shirt signed by the footballers which has since been framed and hung in our board room. We reciprocated by presenting them with a plaque especially made for the occasion which was done and donated to us by Mr Louis Galea from Floriana.

**Thank you** Sheffield United FC for offering such memorable moments to our members. **Thank you** Ms Carley Barnes for suggesting us with your good friends. We hope this event to be the beginning of more similar opportunities to our members.

**Marthese Mugliette**  
**President**



# Grazzi

- Lill-**KMPG** li ta' kull sena jivverifikaw il-kotba u l-kontijiet finanzjarji
- Lit-**Times of Malta** li tiriklama b'xejn l-Assoċjazzjoni tagħna.
- Lis-**Sinjuri Mary Runza u Jessica Curmi** u lill-grupp kollu għall-għajnuna u s-sapport kontinwu tagħhom. Fiż-żmien tal-Milied dawn ġentilment ħadu ħsieb jagħmlu *fundraising* għall-Assoċjazzjoni tagħna.
- Lill-**Kumitat Qlub Ġenerużi** fi ħdan il-**Kumpanija Trelleborg Sealing Solutions Malta**, lill-**P. Cutajar Co. Ltd.**, lill- **KPMH Holding Ltd.**, lill-**Grand Priory of Malta**, lid-**Down Syndrome Association of Central Kentucky**, lis-**Sinjuri Giacomazzi**, lil **Ms Marysa Portelli** għall-għotja finanzjarja tagħhom.
- Lill-**Middlesea Valletta Life Assurance Company Ltd** li anke din is-sena kompliet tagħtina l-appoġġ permezz ta' hlas ta' polza tal-assigurazzjoni tagħna.
- Lill-**Commanderjay Music Entertainment** għas-servizz li dejjem jagħtuna kull u meta jkollna bżonn mingħajr hlas.
- Lis-**Sur Louis Galea** li ħadem u sponsorja l-plakka sabiħa li nġhatat lil Sheffield United FC bħala tifkira tal-okkażjoni.
- Lill-**Aġenzija Żgħażaġh** għall-opportunità u s-sapport li tawna biex fis-sajf li għadda sar B-B-Que għall-membri u l-familjari tagħhom.
- Lill-**Best Print Co. Ltd** li kontinwament jagħtuna s-sapport u l-għajnuna li jkollna bżonn f'dak li għandu x'jaqsam ma' stampar.
- Lil **Dr Robert Tufigno**, il-Legal Advisor tal-Għaqda u lil **Dr Isabella Borg**, iċ-Chief Advisor tal-Għaqda u lil **Fr. Emmanuel Borg Bonello**, id-Direttur Spiritwali tal-Għaqda, li dejjem u kull hin insibu s-sapport u l-għajnuna volontarja tagħhom.

# The Art of Possibility: seamless transition from school to work and adult life

*Kevin Corcoran works in a clerical position at a large accounting firm in Sydney. His CEO, Anthony Bell, is also his mentor.*

There have been so many advances in education and employment strategies that it is now possible to expect that any young person with Down syndrome can have a job upon completing education and becoming an adult. Not just any job, but a job that takes into account the young person's interests, talents, and particular need for support. And not just any employer, but an employer who benefits from the individual's contribution to the enterprise.

This article will summarize what we know about how to make this happen, provide case examples of young people with Down syndrome on their way to satisfying adult careers, and discuss what families can do to encourage these outcomes.

## What we know

Research has shown that youth who have work experience in authentic work environments, that is, in real workplaces, are several times more likely to be employed as adults as those who do not have this experience. Moreover, this is the case regardless of the disability label or the level of support needed. In one study of a high school work program we helped develop in the US, almost 90% of 3,000 special education students who participated in a work experience succeeded in finding and completing the work placement (Luecking & Fabian, 2000). Students with intellectual disabilities performed as well as students with all other disabilities. One year after exiting school, work success continued at a rate several times higher than what has been typical for this category of youth. This suggests that with the proper opportunity and support there is no reason not to expect employment success for everyone.



In the same study, we found that almost 80% of the employers wanted the youth to continue in employment with the company. This suggests that once youth are on the job they can perform to the employer's satisfaction. Just as important, this suggests that it is the youth's potential contribution in the workplace that can be the cornerstone to promoting their employment, as opposed to promoting the notion that it is a charitable thing to hire people with disabilities.

These outcomes, unfortunately, are still far from the norm in the U.S. and elsewhere. Unemployment and underemployment for people with all disabilities, especially intellectual disabilities, is still far too common. However, the findings cited above suggest what is possible if families, schools, and adult employment services adopt an approach that presumes employment for all and that uses strategies that have been especially effective are "transition service integration" and "customized employment."

## Transition service integration

We know that many young people with Down syndrome will need support and accommodation before and after they exit school to experience and sustain employment success. Without the collaboration of schools and adult employment programs it is likely that young persons with disabilities will have very dim prospects of ever becoming employed – or if they do, of sustaining employment. One way to insure a seamless transition from school to adult employment is for youth to become employed prior to school exit and to be supported in keeping that job upon finishing their education. The steps to make this happen include:

- Throughout secondary school years organize several opportunities for students to have work experiences that expose them to work environments and that allow them to develop preferences about work.
- In the last year in school plan for a real paid job by focusing on the positive traits and the personal preferences of the individual.
- Adult employment programs working with school personnel to support the student in the job.
- The student exiting school with the same job and the same adult organization providing support.

In this scenario the young person's first day after school is the same as the day before: a seamless transition from school to adult employment occurs. Many times,

due to the nature of the disability or personal circumstances these jobs are "customized."

## Customized employment

Many young people with Down syndrome have not been considered likely candidates to apply for standard or advertised jobs due to lack of work experience, limited range of skills, stamina, and/or unique accommodation and support needs. However, successful employment can be achieved through job development that identifies employers who can benefit from the youth's particular attributes in alternative, customized ways. Customizing employment often entails carving tasks from existing job descriptions and assigning them to the youth, assigning duties that are created from a list of tasks that employers need to have accomplished, and/or re-structuring job assignments so that tasks are shared with other employees. Thus, the individual has a "customized" job description.

One important feature of effective customized employment is negotiation with employers for task assignment and working conditions. The individual job seeker may not only require task assignments that are customized, but working conditions that are also customized, such as scheduled, pay, and unique accommodations. In any circumstance, the negotiation is considered successful when it is clear that the employer will benefit from the individual's presence in the workplace.

**Richard Luecking**

Source:- VOICE September 2010

## A day in a lifetime for Essien

Remembering the days we spent in England to watch Essien parading Sheffield United makes me shiver till today.

It all started when Ms Marthese Mugliette phoned up my wife Marija to tell her the news that Essien was chosen personally from the Director of Sheffield United to be a mascot in one of the oldest derbies in the story of the English football. His exact words where Essien stole the hearts of the team and so we want him here for the derby. I remember the exact words my wife told me on the phone because I was not there at the time Marija received the news, she was told, "Are you sitting down, Essien has been chosen to be a mascot with Sheffield United in England!!" I was astonished.

A lot of emails passed between me and the Director of Sheffield United Mr. Dave McCarthy so that the day will be perfect for Essien.

We left Malta on the 14<sup>th</sup> October and as a coincidence it was Essien's 6<sup>th</sup> birthday. As we arrived at the hotel we found Dave waiting for us and even had the time to come and welcome us. He presented a Sheffield United gear with Mifsud printed on the back. The lovely staff of the hotel even gave a small present to Essien for his birthday.

On Sunday we were all up by 7am took a good breakfast and off we went to the stadium. There we met all the team involved for this special day. We first started off with a briefing on what was going to happen and so on. We then went to visit the manager of the club and Essien, together with the other mascots went to meet the players. They took quite a few photos with the players. We were taken around the ground showing us the control room and the part where the commentators are.



Essien, together with the other mascots got the chance to play some football in front of 28,000 and more spectators. As noon was approaching Essien was ready to parade the players onto the pitch and I am sure he will never forget this moment.

I can't express the joy we felt as parents and the joy Essien had as to date he still talks about it.

**Roger Mifsud**

## World Down Syndrome Day

**PRESS RELEASE - United Nations adopts resolution to designate 21 March as "World Down Syndrome Day" from 2012 - Down Syndrome International, 16 November 2011**

Wed, 2011-11-16

**PRESS RELEASE - FOR IMMEDIATE RELEASE ON WEDNESDAY 16 NOVEMBER 2011**



800 births worldwide, and to promote the inherent rights of persons with Down syndrome to enjoy full and dignified lives and

Down Syndrome International is delighted to announce that a resolution to designate 21 March as "World Down Syndrome Day", to be observed every year beginning in 2012, was adopted by consensus during the plenary meeting of the Third Committee of the United Nations General Assembly on Thursday 10 November 2011.

The resolution was proposed and promoted by Brazil, following an original request by the Brazilian Federation of Down Syndrome Associations, who worked with Down Syndrome International (DSi) and its members to launch an extensive campaign to generate international support. The resolution was eventually co-sponsored by 78 UN Member States.

Down syndrome groups and associations around the world campaigned for their governments to co-sponsor the resolution. In addition, DSi launched an international petition for the adoption of World Down Syndrome Day by the UN. This received more than 12,000 signatures in a 2 week period and was presented to the Chair of the Third Committee.

DSi has coordinated World Down Syndrome Day (WDSD) since 2006, held on 21 March (21/3) to signify the uniqueness of the triplication (trisomy) of chromosome 21 which causes the genetic condition Down syndrome. The aim of the day is to raise awareness and understanding of a condition which affects approximately 1 in

be active participants in their communities and society.

Activities and events which take place on this day typically showcase the abilities and accomplishments of persons with Down syndrome and encourage independence, self-advocacy and freedom for persons with Down syndrome to make their own choices. To date, WDSD has been observed in over 60 countries around the world.

From 2012, the United Nations will invite all its Member States, relevant organisations of the UN system, international organisations, as well as civil society, including non-governmental organisations and the private sector, to observe WDSD and actively raise public awareness of Down syndrome.

This will ensure a major step forward towards our goal for WDSD to be observed and celebrated by persons with Down syndrome, their families and friends, those who live and work with them and all persons who wish to promote and ensure quality of life and human rights for all persons with Down syndrome.

DSi would like to thank everyone who has supported this campaign, with particular thanks to the Government of Brazil, the Brazilian Federation of Down Syndrome Associations, all of our member organisations who appealed to their governments for support, and to everyone who signed our international petition.

# DISKORS AMMINISTRATTIV

## tas-Segretarju Ġenerali – 29 ta' April 2011

Għaddiet sena mill-aħħar Laqgħa Ġenerali Annwali li saret ukoll fl-aħħar ta' April 2010 u gie maħtur il-Kumitat il-ġdid biex imexxi lill-Għaqda għal sentejn. Sfortunament l-attendenza għal din il-laqgħa kienet, wieħed jista' jgħid, fjakka u l-anqas rajna nies godda jersqu 'l quddiem biex jagħmlu parti mill-Kumitat. L-Għaqda mhux iċ-Ċentru li batejna biex nakkwistawh, imma kull wieħed u waħda minna lkoll li flimkien mal-Kumitat nagħmlu hilitna biex bit-tmexxija għaqlija u bl-għajnuna tagħkom, il-koll nimbuttaw aktar 'il quddiem l-interessi ta' uliedna.

Huwa ferħ importanti, kemm għall-membri u kemm għall-Għaqda, li l-interess, il-partecipazzjoni u s-sapport fix-xogħol tal-Kumitat jibqa' ħaj biex il-Kumitat ikompli jstinka għall-benefiċċju tal-persuni li għandhom *Down syndrome*. L-appell lill-membri ma jonqosx biex hadd ma jibqa' lura milli jressaq xi suġġerimenti jew problemi li jolqtu lill-persuni *Down syndrome* u li l-membri jhossu li l-Kumitat jista' jaħdem fuqhom.

L-għan ewlieni tal-Kumitat taħt id-direzzjoni tal-President preżenti kien u għadu li naħdmu fuq problemi li jolqtu direttament lil uliedna, li wieħed jista' jgħid huma diversi u komuni mal-maġġoranza tal-membri. Il-problemi li l-aktar kienu fuq quddiem tal-ħidma matul is-sena li għaddiet kienu l-problemi tas-saħħa għal adulti u tfal ta' 'l fuq minn erbatax-il sena u l-problemi tat-taħriġ għall-ħajja indipendenti u xogħol adegwat għaž-żgħażaġh *Down syndrome* li jixtiequ jaħdmu.

Biex inżommu l-Għaqda ħajja hemm bżonn l-impenn tal-membri kollha. Bhal kull sena nagħmlu appelli sabiex nies godda jersqu 'l quddiem, kemm jekk jaħsbu li jistgħu jagħtu kontribut fit-tmexxija tal-Kumitat kif ukoll biex joffru s-servizzi u l-għajnuna tagħhom meta jkun hemm bżonn.

Wara sena oħra ta' ħidma huwa xieraq li niġu quddiemkom biex nagħtu rendikont tal-qagħda finanzjarja u tax-xogħol li twettaq mill-Kumitat għal ġid tal-Għaqda u l-membri kollha.

### Attivitajiet

L-Għaqda organizza diversi attivitajiet, imma wieħed irid jgħid li l-konkorrenza għal dawn l-attivitajiet mill-membri qegħda tonqos minn sena għall-oħra.

Il-party tal-Milied sar il-Canifor Hotel Qawra nhar il-Ħadd 19 ta' Diċembru 2010. Kien hemm ħidma intensiva biex norganizzaw attività differenti minn tas-soltu u post addatta għall-bżonnijiet tal-Għaqda biex niċcelebraw l-attività f'ambjent pjaċevoli. Il-Kumitat organizza kien tal-fehma li l-Canifor Hotel kien l-aktar post addattat għall-Għaqda biex niċcelebraw dan iż-żmien ta' ferħ ma' xulxin u giet organizzata iklja buffet bil-mużika waqt din l-attività li giet ipprovduta minn Commanderjay Music Entertainment. Bhas-sena ta' qabel ma tqassmux rigali u s-sussidju tar-rigal lill-membri *Down syndrome* gie mdawwar f'għajnuna diretta u dan billi l-Għaqda ħallset għall-persuni *Down syndrome*.

Attività oħra fiż-żminijiet tal-Milied u li tkun mistennija ħafna miż-żgħażaġh tagħna tkun id-*disco*. Din l-attività saret fis-27 ta' Diċembru 2010 fis-sala tal-iScouts il-Furjana. Barra d-*disco* kien hemm ukoll riċeviment żgħir u l-mużika waqt din l-attività kienet ukoll f'idejn *Commanderjay Music Entertainment*.

Il-Jum Dinji tad-Down Syndrome huwa jum speċjali u diġà ilu sitt snin jiġi ċelebrat mad-dinja kollha. Għal dan il-għan l-Għaqda organizza numru ta' attivitajiet biex tikkommemora dan il-jum:

L-ewwel attività saret il-Ħadd 20 ta' Marzu

fejn giet ċelebrata quddies fil-Knisja ta' Santu Wistin (Santa Rita). Il-kant waqt din il-quddies kien f'dejn il-grupp immexxi mis-Sinjura Mary Runza, il-Presidenta Onorarja tal-Għaqda u mid-Dottoressa Jessica Curmi. Dan il-grupp għandu sehem kbir fl-Għaqda tagħna għaliex ta' kull sena jagħmel *Christmas carolling* bil-ġbir kollu jmur għall-Għaqda tagħna.

It-tieni attività saret fil-ġurnata tal-21 ta' Marzu. Din l-attività kienet tirrikjedi ħafna ppjanar u taqtiġ ta' qalb, imma minkejja kollox wasalna għall-iskop tagħna biex inqajmu aktar kuxjenza għall-persuni li għandhom *Down syndrome* mal-ogħla dirigenti tal-Gvern u tal-partiti politiċi. Ressaqnielhom il-problemi li persuni *Down syndrome* jiffaċċjaw f'kull qasam tal-ħajja u l-kwalità ta' ħajja għall-persuni *Down syndrome* fejn tidhol is-saħħa, l-edukazzjoni, id-dinja tax-xogħol, *self advocacy*, il-pensjoni, il-ħajja indipendenti u r-rikreazzjoni. Fl-ewwel laqgħa li kienet mal-Onor Prim Ministru Dr. Laurence Gonzi ġewwa Kastilja ħadu sehem il-President tal-Għaqda, il-Viċi President, is-Segretarju u l-PRO tal-Għaqda. Wara din il-laqgħa saret laqgħa oħra mar-rappreżentant tal-Gvern Dr Stephen Spiteri, mal-Kap tal-Partit Laburista l-Onor. Dr. Joseph Muscat u mal-Onor. Dr. Justyne Caruana, kelliema għall-Familja u Ugwaljanza u mas-Sur Michael Briguglio, Chairperson Alternattiva Demokratika u ma' Ms. Claire Azzopardi Lane kelliema għad-Diżabilità. Din il-laqgħa saret fiċ-Ċentru quddiem numru ta' membri tal-Għaqda u membri tal-Kumitat. L-istampa kienet mistiedna imma kien biss is-Super One li baġhat il-*crew* u *reporter* tiegħu u kien hemm ukoll id-DOI.

F'dan il-jum ħadna sehem ukoll fil-programm Inwar ippreżentat minn Ms Susan Mulvany. Is-suġġett itratta fuq il-Ġurnata Dinjija tad-Down Syndrome,

ingħata tagħrif dwar il-kundizzjoni *Down syndrome*, tkellimna dwar dak li qegħdin naħdmu fuq bħalissa – l-Edukazzjoni wara s-sittax-il sena, l-Impjeg u l-Ħajja Indipendenti għal uliedna. Waqt il-programm daħlu wkoll xi telefonati mis-semmiegħa.

Barra minn dawn l-attivitajiet, wieħed ma jridx jinsa l-Quddies ta' kull l-ewwel Ġimgħa tax-Xahar fiċ-Ċentru, fejn wara wieħed ikun jista' jieħu l-kafè u pastizzi u jilgħab it-tombola.

### It-Tletin Anniversarju

Din is-sena l-Għaqda qed tfakkar it-tletin sena mit-twaqqif tagħha. Il-Kumitat qed jaħseb u jaħdem biex itella' żewġ konferenzi – waħda f'Malta u l-oħra f'Għawdex. Fil-konferenza ta' Malta se jkun mistieden kelliem barrani. Iż-żewġ konferenzi se jittrattaw temi differenti li jolqtu lil uliedna. Il-konferenzi se jsiru s-Sibt 29 t'Ottubru u s-Sibt 5 ta' Novembru 2011. Nisperaw li kulhadd jagħmel mezz biex jattendi għal dawn il-konferenzi u tinfirmaw ruħkom dwar dak li jolqot lil uliedna.

### Servizzi tal-Għaqda

Matul din is-sena ta' ħidma l-Għaqda sabet ħafna diffikultajiet biex tipprovd l-istess servizzi li konna qegħdin nagħtu qabel minħabba nuqqas ta' għalliema jew finanzi.

### Il-Programm 'Reach'

Is-servizz gie fit-tmiemu fl-aħħar ta' Settembru 2009 minħabba' li l-ftehim mall-Fondazzjoni Eden u r-Razzett tal-Ħbiberija ma ggeddidx u dan minħabba raġuni ta' finanzi u responsabilitajiet tal-programm. Skont l-impenn li l-Kumitat kien daħal għalih, l-Għaqda laqqgħet lill-ġenituri u wliedhom fiċ-Ċentru u waqt ċerimonja żgħira l-President tal-Għaqda ppreżentat lill-ġenituri ta' dawk li kienu

attendew għal dan il-programm b'čekk li kien sussidju għal parti mill-mizata li kienu f'allsu lill-Eden. Din l-għotja ta' flus kienet possibbli grazzi għall-fondi li l-Għaqda kienet ibbenifikat mill-iStrina fl-edizzjoni tal-Milied 2006.

### Programm għall-Adulti li jwassal għall-Hajja Indipendenti

Wara li kien waqaf il-programm 'Reach', l-Għaqda ħadmet ħafna biex terġa' tibda programm għall-adulti. Saru kuntatti u laqgħat ma' professjonisti f'dan il-qasam biex jinbeda programm addattat li jwassal liż-żgħażaġh tagħna għall-impjeg u għall-ħajja indipendenti. Saret ukoll laqgħa għall-ġenituri li kienu urew xi ftit ta' interess fir-rigward. Sfortunatament, meta ġejna biex niġbru n-numru ta' dawk li verament riedu jibbenefikaw minn dan il-programm, in-numru ta' dawk interessati u li kienu lesti għal dan l-impenn kien żgħir wisq biex stajna nkomplu nibnu fuq dak li kien ġa għandna f'idejna. Madankollu, minkejja dan ir-rizultat negattiv, l-isforzi tagħna fir-rigward u anke diskussjonijiet mal-awtoritajiet għadhom qed isiru biex forsi nidhlu għall-'public partnership'. S'issa l-isforzi tagħna kollha fir-rigward għadhom ma ssarfux f'rizultati positivi. Il-proċess huwa diffiċli u t-triq hija twila.

### Job Skills – Employability Programme

Fl-14 ta' Frar ġie mniedi kors ġdid mogħti mill-ETC, bil-partecipazzjoni u kollaborazzjoni tal-Fondazzjoni Equal Partners u l-Assoċjazzjoni Down Syndrome. Dan il-kors qiegħed isir mal-membri adulti tagħna fiċ-Ċentru tagħna. Kull grupp huwa magħmul minn ħames membri adulti Down syndrome. Huma qed jingħataw jitharrġu biex jakkwistaw ħiliet biex 'il quddiem ikunu jistgħu jidhlu fid-dinja tax-xogħol. Kull programm ta' taħriġ qed isir fuq

għaxar lezzjonijiet tliet darbiet fil-ġimgħa wara nofsinhar. Kull min jibbenefika minn dan l-programm jingħatawa ċertifikat.

### Lezzjonijiet tal-Crafts

Dan is-servizz ukoll ra n-numru ta' membri interessati jikber. Dan il-grupp jiltaqa' fiċ-Ċentru tagħna kull ħmistax nhar ta' ġimgħa għall-membri li għandhom 'il fuq minn sittax-il sena.

### Aerobics

Minħabba impenji personali l-għalliema tal-Aerobics ma kinetx f'pożizzjoni li tkompli tagħti dawn il-lezzjonijiet. Domna xi ftit biex sibna sostituta. Il-kera tal-*Guardian Angel School*, fejn kienu jsiru dawn il-klassijiet, għolew ħafna u bejn b'din l-ispiża kif ukoll b'dik tal-għalliem, kull lezzjoni kienet sejra tiswa ħafna għal kull membru u għall-Għaqda. Wara ħidma kbira u, nerġa' ngħid ħafna qtigħ ta' qalb, issa jidher li kollox ġie f'postu u nistgħu nerġġu noffru dan is-servizz grazzi għall-British Legion, għas-Sur Peel u għall-għalliema l-ġdida.

### Lezzjonijiet tal-Computer

Wara xhur li l-programm kien ilu wieqaf minħabba nuqqas ta' għalliema, issa dan il-programm reġa' beda u hu maħsub li jieqaf fl-aħħar ta' Ġunju, meta ċ-Ċentru jagħlaq għas-sajf.

### Il-Librerija

L-Għaqda qiegħda tagħmel sforz biex jerġa' jkollha l-librerija. Bdejna mill-għamara billi xtrajna librerija ġdida u bdejna nixtru kotba godda li ħsibna jkun ta' interess għalina l-membri, għall-għalliema u għat-terapisti. Il-flus li bihom bdejna nixtru l-ewwel kotba kienu mogħtija l-Għaqda mill-*Association of International Women in Malta*. Il-lista ta' kotba li diġà nixtraw kienet ġiet iċċirkolata fil-ċirkolari tal-5 ta' Ottubru 2010. Bħalissa qed nistennew xi kotba oħra jaslulna u hemm il-ħsieb li nkomplu nixtru kotba

oħra li naħsbu li jkun ta' għajnuna għal kulħadd. Il-librerija hija ntiza biex tintuza minn kulħadd, membri u mhumiex, imma dejjem taħt kontrol strett biex ma jerġax jiġri li kotba mislufin qatt ma jerġu jiġu ritornati lura u ma nkunux nafu għand min qiegħdin. Inhegġgukom tagħmlu użu mill-librerija u xxerrdu l-kelma.

### Premises

Il-ħolma tal-Kumitat tal-passat qiegħda tkompli ssir realtà. L-ewwel li jkollna Ċentru tagħna u t-tieni li jiġi wkoll irrangat kemm jista' jkun malajr biex inkunu f'pożizzjoni li noffru aktar servizzi u jkun aktar akkoljenti. It-tielet ħolma hija li ċ-Ċentru jiġi aċċessibbli għal kulħadd. Grazzi li l-permess ta' Pio Fenech reġa' ġie mġedded mill-Awtorajiet għal sena oħra u b'hekk għadu ssekondar mal-Għaqda, stajna nkompli bix-xogħol. Għalkemm baqa' ħafna xi jsir, żgur li wieħed jista' jara d-differenza anki mis-sena l-oħra 'l hawn.

### Magazine

Il-*magazine* taħt id-direzzjoni tal-Bord Editorjali tkompla b'determinazzjoni kbira. Nixtieq infakkar fil-bżonn kbir li jeżisti biex nirċievu xi esperjenzi, ritratti u jew xi artikli sabiex jiġu ppubblikati fil-*magazine*. Jekk ikollkom bżonn ta' xi għajnuna, il-membri tal-Kumitat ikunu lesti jgħinukom b'xi kitba u/jew intervista, jekk hemm bżonn fid-dar tagħkom stess.

Il-*magazine* qiegħed jiġi ppubblikat b'diffikultà kbira, anki finanzjarja. 50 fil-mija tan-nefqa għall-posta tingħata lura mill-Kummissjoni Nazzjonali Persuni b'Diżabilità wara applikazzjoni. Il-flus biex jithallas dan il-*magazine* iridu jiġu mill-ġbir

ta' fondi, għax reklami, jew għajnuna diretta jew indiretta biex intaffu l-ispejjeż tiegħu m'għadniex insibu. Tant li illum qiegħdin noħorġu edizzjoni waħda biss fis-sena minflok tnejn bħalma kien isir qabel.

### Konklużjoni

Reġġet għaddiet sena oħra! L-impenn tal-President tal-Għaqda u tal-Kumitat kollu baqa' sod u dejjem iħares 'il quddiem biex pass wara pass inħottu hitan li jiffaċċjaw persuni *Down syndrome*, biex flimkien mal-familji nakkwistaw ħajja aħjar għall-membri tagħna u għal dawk kollha li għandhom *Down syndrome*. Inkun qed nonqos jekk ngħid li ma baqax xogħol, sar ħafna xogħol, imma t-triq hija twila u d-diffikultajiet huma kbar anki dawk finanzjarji. Hemm bżonn li membri b'ideat godda jieħdu posthom fil-Kumitat, biex dawk li ilhom iservu jkun jistgħu jerhu posthom, u b'hekk il-Kumitat jiġġedded u jkun jista' jimxi 'l quddiem u jiffaċċja l-isfidi b'enerġija halli l-Għaqda tkompli tikber. Inħajjar membri godda jidhlu fi hdn l-Għaqda.

Nixtieq nagħlaq billi nringrazzja lilkom preżenti talli ġejtu illum u lill-membri kollha tal-Kumitat, helpers u professjonisti għall-ħidma tagħhom fi hdn l-Għaqda.

Issa wasal il-mument fejn intkom il-membri għandkom l-opportunità li titkellmu, tissuggerixxu u tqajmu punti li għandhom x'jaqsmu mal-Għaqda. Kull membru huwa importanti għall-Għaqda u għandu x'jagħti lill-Għaqda u l-kontribuzzjoni tagħkom hija mistennija.

**Antoine Gauci**  
Segretarju

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