



UNFOLD

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THEIR
POTENTIAL**
(Y)OUR
**RETURN ON
INVESTMENT**

AGEING WITH SPINA BIFIDA
AND HYDROCEPHALUS
- NO TIME TO LOSE -

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“We’ve grown beyond the boundaries of established medical research. We are the pioneers. Many adults with Spina Bifida know more about their bodies than the physicians they see.”

Dr. Timothy Brei, born with Spina Bifida

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INTRODUCTION

In 2012, the European Year for Active Ageing and Solidarity between the Generations, the International Federation for Spina Bifida and Hydrocephalus (IF) is issuing this call to action to draw attention to the challenges faced by people with Spina Bifida and Hydrocephalus as they age in three key areas: health, employment, and social inclusion.

During IF's International Conference in Dublin in 2010, the message was clear: "We have no time to lose. Adults with Spina Bifida and Hydrocephalus need and deserve lifelong coordinated care." In 2011, this important statement was repeated in a number of surveys among IF's EU members and it became the main topic during IF's EU workshop "Adults, and now?" on access to multidisciplinary care in Leuven. A workshop which took place during the conference "Spina Bifida and Hydrocephalus Anno 2011". This year, at IF's 2012 International Conference in Stockholm, the IF General Meeting unanimously approved our call to action.

It is imperative that policy makers take urgent action to combat the problems faced by people with Spina Bifida and Hydrocephalus as they age. They are the first with these conditions to reach their senior years and want to enjoy their older years in the same manner as other people their age.

Due to improved medical care, it is predicted that the numbers of elderly people with Spina Bifida and Hydrocephalus will rise dramatically over the next few decades.

Taking action now to ensure that these people have the care and support they need to lead healthy and active lives into old age is vital; doing nothing could have a severe economic and social impact.

To support this call to action, IF has brought together evidence from people with Spina Bifida and Hydrocephalus, the people they live with, their colleagues, friends and family members, academic experts and medical professionals. A survey was distributed online and responses were received from Austria, Belgium, Croatia, Germany, Italy, Ireland, the Netherlands, Norway, Portugal, Slovakia, Spain, Sweden, Switzerland, Turkey and the UK. Those from outside of Europe responded as well and information was received from Australia, Canada, New Zealand and the USA.

All over the world people with Spina Bifida and Hydrocephalus are facing the same fears and barriers, which put at risk their health, independence and quality of life. Access to multidisciplinary clinics¹ with appropriate specialist care can help allay these fears and enable people with Spina Bifida and Hydrocephalus to achieve a quality of life equal to others.

¹ Information on multidisciplinary care is available in the section "Background".

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CALL TO ACTION

Today, people with Spina Bifida and Hydrocephalus are living longer than ever before. They too want to age actively and healthy, and contribute to society. Yet currently they fear for their future and their lives, because knowledge about their conditions in advanced age is lacking and coordinated care and support is unavailable.

It is vital that steps are taken to resolve this urgently, as the number of people with Spina Bifida and Hydrocephalus living into old age is expected to rise rapidly over a short period of time. Waiting any longer to tackle this problem will result in serious economic and social impacts; and major challenges for people with Spina Bifida and Hydrocephalus and their families.

Spina Bifida is one of the most complex birth defects compatible with life (Bunch et al, 1972; Liptak and El Samra, 2010). It is often accompanied by a medical condition called Hydrocephalus. Scientific advances have ensured that the majority of newborns with Spina Bifida and Hydrocephalus who do receive timely and correct treatment can reach adult years and live valuable and meaningful lives.²

However, not all children born with Spina Bifida and Hydrocephalus receive the necessary and appropriate treatment and care, and neither do all adults with these conditions. Based on negative assumptions about their future quality of life, treatment can be refused or abandoned. Lack of knowledge in the medical field can mean that symptoms go unnoticed, or wrong diagnoses are made. This may lead to long-time stays in hospital, life in an institution, or even death.

With non-treatment and lack of knowledge resulting in no life or a very poor quality of life, the already existing negative stereotyping is reaffirmed and enhanced.

On January 23rd, 2011, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) became legally binding for the EU member states. This means that all persons with disabilities should have equal rights and equal opportunities and that ageing people with Spina Bifida and Hydrocephalus should have the right to participate fully and equally in society and economy including in the labour market.

Nevertheless, it has been noted that for people with Spina Bifida and Hydrocephalus levels of independence, participation rates and employment rates are still much lower than expected.³ They experience a multitude of disabling barriers - physical, financial, technical and attitudinal - which prevent them from accessing adequate support and services and achieving a standard of living equal to those without disabilities.

In order for children, youngsters and adults with Spina Bifida and Hydrocephalus to reach their full potential, age actively and healthy, and achieve a good quality of life, they need the right health care and appropriate assistance and support throughout their lifetime. To be as effective and efficient as possible, this care and support needs to be coordinated. Extensive research and experience has shown that multidisciplinary clinics

² *Spina bifida outcome: a 25-year prospective*, Bowman RM, McLone DG, Grant JA, Tomita T, Ito JA; *Pediatr Neurosurg*. 2001 Mar;34(3):114-20

³ *Guest editorial; Brei T, Mukherjee S; Journal of Pediatric Rehabilitation Medicine: An Interdisciplinary Approach 1 (2008) 281-282; IOS Press*

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are the best solution to provide coordinated treatment, care and support for those born with Spina Bifida and Hydrocephalus.^{4,5,6,7,8,9,10}

We call on European and national policymakers to:

- . recognise that the ageing and expanding group of persons with Spina Bifida and Hydrocephalus is facing increasing and serious challenges to live healthy lives and fulfil their potential and that swift action is required;
- . end health inequalities now by ensuring that all persons born with Spina Bifida and Hydrocephalus have access to the appropriate treatment, care and support, provided to them in multidisciplinary clinics;
- . promote social inclusion and employment of adults with Spina Bifida and Hydrocephalus, starting with the promotion of inclusive education and rehabilitation for children and adolescents with these conditions.

4 Care coordination in the spina bifida clinic setting: current practice and future directions, Brustrom J, Thibadeau J, John L, Liesmann J, Rose S; *J Pediatr Health Care*. 2012 Jan-Feb;26(1):16-26.

5 Development of health support services for adults with spina bifida, West C, Brodie L, Dicker J, Steinbeck K; *Disabil Rehabil*. 2011;33(23-24):2381-8.

6 From transition challenges to successes: establishing a spina bifida adult care clinic, Hobson B; Abstract presented at Second World Congress on spina bifida research & care

7 Introduction: Spina bifida—a multidisciplinary perspective, Fletcher JM, Brei TJ; *Dev Disabil Res Rev*. 2010;16(1):1-5.

8 Optimizing health care for children with spina bifida, Liptak GS, El Samra A; *Dev Disabil Res Rev*. 2010;16(1):66-75.

9 Optimizing health care for adults with spina bifida, Webb TS; *Dev Disabil Res Revs*, 16: 76–81. doi: 10.1002/ddr.99

10 Treatment of myelomeningocele: a review of outcomes and continuing neurosurgical considerations among adults, Platt JH Jr; *J Neurosurg Pediatr*. 2010 Dec;6(6):515-25.

SUMMARY OF KEY ISSUES

- . People with Spina Bifida and Hydrocephalus are living longer than ever before and have the right to the enjoyment of the highest attainable standard of health throughout their lifespan.
- . The number of people ageing with Spina Bifida and Hydrocephalus will increase in the years to come.
- . Little is known about the progress of these conditions as people age and more research is urgently needed to ensure that people with Spina Bifida and Hydrocephalus maintain their health and can live their lives equal to others.
- . Due to the complex physical, psychological and social needs of people with Spina Bifida and Hydrocephalus, specialised care in a multidisciplinary setting is imperative.
- . Multidisciplinary care should be available to people with Spina Bifida and Hydrocephalus of all ages and not solely in the childhood years.
- . Family members and partners of adults with Spina Bifida and Hydrocephalus are ageing themselves and may no longer be able to support their loved ones.
- . Adults with Spina Bifida and Hydrocephalus have the right to work, to live independently and to participate in all aspects of life. However, lack of mobility, lack of adaptive equipment, lack of education and support, lack of accessibility, and discrimination and lack of social acceptance create serious barriers to exercising these rights.

RECOMMENDATIONS

IF urges governments to undertake immediate, effective and appropriate measures to enable persons with Spina Bifida and Hydrocephalus, both children and adults, to obtain and maintain maximum independence and full inclusion and participation in all aspects of life.

To this end, IF recommends that governments

- . combat stereotypes and prejudices through awareness campaigns which promote positive perceptions and greater social awareness towards persons with Spina Bifida and Hydrocephalus;
- . enable access to multidisciplinary clinics and habilitation and rehabilitation services specific to the complex needs of persons with Spina Bifida and Hydrocephalus;
- . improve accessibility of education, employment and the living environment;
- . ensure access to quality mobility aids, devices, assistive technology and forms of live assistance at affordable cost;
- . facilitate and support capacity-building through the development and strengthening of national and/or local Spina Bifida and Hydrocephalus associations and (parent) support groups;
- . to encourage and facilitate international cooperation in research and access to scientific and technical knowledge concerning all aspects of living with Spina Bifida and Hydrocephalus.

BACKGROUND

WHAT ARE SPINA BIFIDA AND HYDROCEPHALUS?

Spina Bifida is a neural tube birth defect which occurs within the first four weeks of pregnancy. The spinal column fails to develop properly, resulting in varying degrees of permanent damage to the spinal cord and nervous system. The health of persons with Spina Bifida and Hydrocephalus can vary widely based on age, level of damage to the spinal cord, number and severity of co-morbidities, degree of self-care skills, amount of family and community support, and access to medical care.⁹

The primary characteristic of **Hydrocephalus** is excessive accumulation of fluid in the brain. Although hydrocephalus was once known as "water on the brain," the "water" is actually cerebrospinal fluid - a clear fluid surrounding the brain and spinal cord. The excessive accumulation of this fluid results in an abnormal dilation of the ventricles (spaces) in the brain, causing potentially harmful pressure on the tissues of the brain.

HEALTH

There is no permanent cure for Spina Bifida and Hydrocephalus, and people born with these conditions need lifelong follow-up care and support to prevent or treat possible additional health issues. Vertebrae may start to fuse (tethered cord syndrome), kidneys may start to fail, bladder infections and bowel problems may develop, the shunt that controls the Hydrocephalus may start to malfunction. Due to paralysis and insensitivity to pain in the lower body area, pressure sores may develop and go unnoticed. If left unattended, the only remaining option could be amputation of a foot or leg. Damage to the central nervous system can also cause cognitive issues.

Apart from medical conditions related to Spina Bifida and Hydrocephalus, there is an increased risk of secondary conditions such as arthritis, osteoporosis, obesity and diabetes emerging as individuals age. These health issues generally associated with ageing may occur at an earlier stage amongst individuals with Spina Bifida and Hydrocephalus. For all concerned it is important to prevent additional health complications.^{11 12 13}

The most common health challenges for people with Spina Bifida and Hydrocephalus are described in more detail below, but more research and cooperation in this area is needed to gain a comprehensive understanding of the health challenges faced by people with Spina Bifida and Hydrocephalus as they age.⁹

Due to the complexity and variability of their health issues, it is important that people with Spina Bifida and Hydrocephalus, young and old, receive proper care throughout their lifespan by health care professionals with up-to-date knowledge about their conditions. There is a continued need for multidisciplinary care throughout the life course and not solely in childhood.

¹¹ *The cost of preventable conditions in adults with spina bifida.* Kinsman SL, Doehring MC; *Eur J Pediatr Surg.* 1996 Dec;6 Suppl 1:17-20.

¹² *Hospitalizations of adults with spina bifida and congenital spinal cord anomalies.* Dicianno BE, Wilson R; *Arch Phys Med Rehabil.* 2010 Apr;91(4):529-35.

¹³ *Self-management, preventable conditions and assessment of care among young adults with myelomeningocele.* Mahmood D, Dicianno B, Bellin M; *Child Care Health Dev.* 2011 Nov;37(6):861-5. doi: 10.1111/j.1365-2214.2011.01299.x.

Reduced kidney function and reduced mobility make you more dependent on others.

The cost of living goes up. You have to pay more to get any quality of life as not everything is provided, i.e. continence pads.

Respondent IF Survey 2012 (Ireland)

Too little specific health care for the older persons with SB&H is available. So a risk will exist that illness will not be treated (in a proper way). Urological problems will increase in many cases and tethered cords as well.

Respondent IF Survey 2012 (the Netherlands)

Lack of knowledge in healthcare systems / services creates barriers. Knowledge on ageing with SB is absent.

Respondent IF Survey 2012 (Norway)

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When the EU ratified the UNCRPD on January 23rd, 2011, it recognized that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.

The highest attainable standard of health for people with Spina Bifida can be reached by ensuring access to free or affordable multidisciplinary clinics and all supplies necessary for their continued optimal health, such as orthopaedic devices and incontinence products.

Health insurance policies in the EU should not create obstacles for people with Spina Bifida and Hydrocephalus in receiving the appropriate treatment, care and support that they deserve.

EMPLOYMENT

The UNCRPD calls for signatories to ensure the rights of those with disabilities to be upheld to the same standard as those without disabilities, including as regards the right to the opportunity to gain a living by working in an area freely chosen by themselves.¹⁴ States are obliged to safeguard and promote the realisation of the right to work. Governments need to recognise the obstacles to employment for those with Spina Bifida and Hydrocephalus and to ensure that policy and practice are working as effectively as possible to ensure their rights are met.

Despite European legislation prohibiting discrimination against people with disabilities and requiring employers to make reasonable adaptations to allow them to take up employment¹⁵, many people with Spina Bifida or Hydrocephalus fear that potential employers struggle to see beyond their disability.¹⁶ This puts them at a disadvantage when applying for work, especially for the elderly generation.

Physical challenges faced by people with Spina Bifida and Hydrocephalus, especially as they age - described in the Health section - greatly increase the difficulty of finding and maintaining a full-time, office-based job with traditional working hours.¹⁷ Having to attend multiple medical appointments can be time consuming, physically enduring, financially burdensome, and in some cases beyond people's ability, but can also cause negative stigma at work. Better understanding of their condition, more flexible working patterns and improved accessibility, both of the environment and the workplace, will enable people with Spina Bifida and Hydrocephalus to become and remain independent and fulfil their potential, even as they age.

“Oblige countries to make public transport accessible for everybody. Support firms when they accept older employees with a disability.”

Respondent IF Survey 2012 (Belgium)

¹⁴ UNCRPD, article 27

¹⁵ Council Directive 2000/78/EC establishing a general framework for equal treatment in employment and occupation.

¹⁶ Particularly in the case of Hydrocephalus, where no disability is initially “visible”, some may feel the need to keep their condition a secret at interview in order to avoid discrimination from employers, which can lead to problems at a later stage.

¹⁷ A survey of people with Spina Bifida conducted by the UK organisation SHINE found that of the 406 respondents above working age, only 140 were in paid employment. 78 of those were working part-time.

People with Spina Bifida and Hydrocephalus need support to learn about their rights and their possibilities. Multidisciplinary clinics in cooperation with local support groups can offer them insight in their condition with regard to job opportunities and information about services they can apply for which will improve their access to paid employment.

SOCIAL INCLUSION

Many people with Spina Bifida and Hydrocephalus are cared for by their parents or other family members, which can present significant difficulties as these relatives age and become less able. Eventually the failing of family support may lead to life in an institution or residential care.

The health problems faced by people with Spina Bifida or Hydrocephalus, such as reduced mobility or incontinence, can limit their ability and willingness to engage socially, which puts them at risk of loneliness and social exclusion. Social services and social security systems can be complex at all times, but particularly for people with Spina Bifida and Hydrocephalus, and especially when they age. Yet they will need these services to maintain their independence for as long as possible.

Local support groups working together with multidisciplinary clinics can offer training and support for people with Spina Bifida and Hydrocephalus to become and remain self-reliant. They also offer the opportunity for people with Spina Bifida and Hydrocephalus to engage with others in a similar situation, and to share experiences and solutions.

“People can work, live full lives, have lovers, an active social life, and have a family, but this doesn't always happen in real life.”

Respondent IF survey 2012 (Turkey)

“In Italy life with Spina bifida is good if there are parents or family, without that it is very very difficult and I think the future will be black!”

Respondent IF survey 2012 (Italy)

Increased care support from national and local authorities is needed to help ease the burden on families and to ensure the right of those born with Spina Bifida and Hydrocephalus to live independently and being included in the community.¹⁸

¹⁸ UNCRPD, article 19, article 26

“States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.”

UNCRPD, article 26, Habilitation and Rehabilitation

THE INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

The International Federation for Spina Bifida and Hydrocephalus (IF) is the world-wide umbrella organisation (INGO) for Spina Bifida and Hydrocephalus organisations, created in 1979. IF's membership consists today of 43 regional and national umbrella organisations for Spina Bifida and Hydrocephalus. IF has intensive contact with regional and national organisations in over 50 countries, spread over five continents. The mission of IF is to improve the quality of life of people with Spina Bifida and Hydrocephalus throughout the world and to decrease the incidence of Spina Bifida and Hydrocephalus through primary prevention.

WHAT IS MULTIDISCIPLINARY CARE FOR PEOPLE WITH SPINA BIFIDA AND HYDROCEPHALUS

Multidisciplinary care developed as a means to provide seamless, holistic care to persons with chronic conditions, involving complex physical, psychological and social needs.

In a multidisciplinary clinic a wide array of specialists work together to ensure that all the needs of their clients are assessed and met in the most effective and efficient way. People are seen as a whole individual and not as a set of separate medical conditions and are actively involved in their treatment. This may improve compliance, attending for treatment investigations and following through with treatment and management plans. For the specialists levels of knowledge and expertise will rise through improved communication, education and cooperation. These benefits will improve the outcome of treatment.

As a client's condition changes over time, the composition of the team may change to reflect the changing clinical and psychosocial needs of the patient.¹⁹

Additionally, a multidisciplinary clinic can also offer an opportunity for parents to meet parents, families to meet families, and for children, youngsters and adults with similar conditions to meet each other.

Case study – Chelsea and Westminster Hospital

The Chelsea and Westminster Hospital was founded in 1992 and operates a multidisciplinary care clinic for adults with Spina Bifida and/or Hydrocephalus. It is one of only two multidisciplinary clinics of its kind in Europe. One of the aims of the clinic is to establish continuity of specialist health care in an adult setting, after children with Spina Bifida and/or Hydrocephalus reach 18 years of age.

The clinic is run by Dr Roger Morgan, a Consultant Physician, who carries out general assessments for each new patient, and SHINE's²⁰ representative Hilary Franklin, who gives advice on all non-medical aspects of living with Spina Bifida and Hydrocephalus, such as employment, social security benefits and support groups. Offering such support is important and an otherwise neglected area, where those with the conditions may have little understanding of the availability of such support.

¹⁹ *Multidisciplinary care planning and teamwork in primary care, Mitchell GK, Tieman JJ, Shelby-James TM; Med J Aust. 2008 Apr 21;188(8 Suppl):S61-4.*

²⁰ *SHINE is a UK registered charity, dedicated to supporting individuals and families as they face the challenges arising from Spina Bifida and Hydrocephalus.*

Each new patient is given a full day appointment where their complete history from birth until present day is assessed and recorded. Without the multidisciplinary approach, such a detailed record would be left unattained. Next all necessary investigations are carried out, e.g. blood tests, renal ultrasounds, MRI scans, X-rays (shunts, orthopaedic), bone density checks and other specialist investigations as required. After this patients attend the multidisciplinary clinic on an annual basis. Additional medical experts such as a physiotherapist, occupational therapist, and neuropsychologist are also available for consultation in the clinic. The occupational therapist can check whether everything in the home is suitably adapted for the patient's needs, e.g. lower level cabinets and units, wet rooms instead of bathrooms, grab rails etc. The neuropsychologist will assess those with Hydrocephalus for problems with memory and sequencing and will be able to give them tips for dealing with this, e.g. ways to spark their memory. In addition this specialist can explain how their condition is likely to affect the type of work they will be able to do and which employment opportunities might be available to ensure they are targeting the right applications.

In between the annual checkups, patients are able to have additional appointments arranged.

The comprehensive nature of the multidisciplinary clinic is critically important for the health outcomes of those with Spina Bifida and Hydrocephalus.

WHAT ARE THE HEALTH ISSUES FACED BY PEOPLE WITH SPINA BIFIDA AND HYDROCEPHALUS AS THEY AGE

In order to inform this position paper, IF consulted people with Spina Bifida and Hydrocephalus, their families and those working with them through an online survey, interviews and focus groups. The following health issues and the resulting impacts were flagged as being of particular risk as people with Spina Bifida and Hydrocephalus age.

Cognitive issues - Fine motor skills are often affected by Hydrocephalus, making certain tasks and activities like sport difficult. Balance and spatial awareness are also often affected. These issues can limit independence and are likely to worsen in later stages of life. Directional skills can be worse and this, compounded with difficulty in following a long sequence of instructions, can make independent travel and outings difficult.²¹

Pressure areas - Pressure sores are more likely in conditions which restrict mobility, such as Spina Bifida, and can become more dangerous if they result in a loss of sensation and circulation.²²

Renal and continence issues - Neuropathic bladder and bowel is a common symptom of Spina Bifida and a poorly managed neuropathic bladder can have a damaging effect on the kidneys. Continence and renal management is difficult throughout the life course, but can be compounded by the ageing process, which in itself increases the risk of incontinence. A large number of people with Spina Bifida rely on intermittent catheterisation, which can become more difficult as dexterity, time management and mobility worsen through ageing.

²¹ IF GLOBAL website: <http://www.ifglobal.org/en/hydrocephalus/living-with-hydrocephalus>

²² IF GLOBAL website: <http://www.ifglobal.org/en/spina-bifida/living-with-spina-bifida>

Social stigma, embarrassment and the often fragmented structure of health services can result in a reluctance to seek help with these issues.

Shunt infection - Whether installed in childhood or adulthood, shunts carry a risk of blockage or infection, which can go unnoticed. Proactive check-ups and monitoring are needed to diagnose these problems, which are often not provided through standard health services but are available through multidisciplinary clinics.

Chronic pain - Spinal, joint and muscle pain and curvature of the spine may become more evident and problematic in the ageing population with Spina Bifida, further reducing mobility and independence.

Obesity and weight issues²³ - Those with disabilities may have less money and thus find it harder to finance a healthier diet and regular exercise, which can put them at a greater risk of being overweight. For those with Spina Bifida, being overweight can put more pressure on weak joints and spinal cords, compounding already limited mobility. The risk of developing osteoarthritis is also greatly increased amongst those who are overweight.

Joint problems and osteoporosis - Osteoporosis especially affects the older population, particularly women. Inactivity, which is more likely amongst those with reduced mobility, can reduce bone density (a major risk factor for the onset of osteoporosis). Since the condition commonly affects the spinal bones, this is a particular concern for those with Spina Bifida.

Tethered cord - The onset of tethered spinal cord syndrome is commonly linked to Spina Bifida and is increasingly likely to occur in the older generation, as there is a narrowing of the spinal column with ageing. In adults, the symptoms of tethered spinal cord can closely reflect those of mechanical back pain, leading to incorrect treatment and diagnosis.

Diabetes²⁴ - As discussed above, people with disabilities can be at a higher risk of obesity: a particular risk factor for diabetes. Both diabetes and limited mobility can cause neuropathy of the feet, resulting in amputation in the worst cases.

Spinal problems - Spinal pain and conditions such as curvature of the spine may become more evident and problematic amongst people with Spina Bifida as they age, making mobility harder and tasks requiring heavy lifting or long walks infeasible.

²³ The number of people who are overweight or obese has more than doubled since the 1980s, with at least 2.8 million adults dying each year as a result of related health issues (WHO, 2012 <http://www.who.int/mediacentre/factsheets/fs311/en/>)

²⁴ 346 million people globally are estimated to suffer from diabetes (WHO, 2011)

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