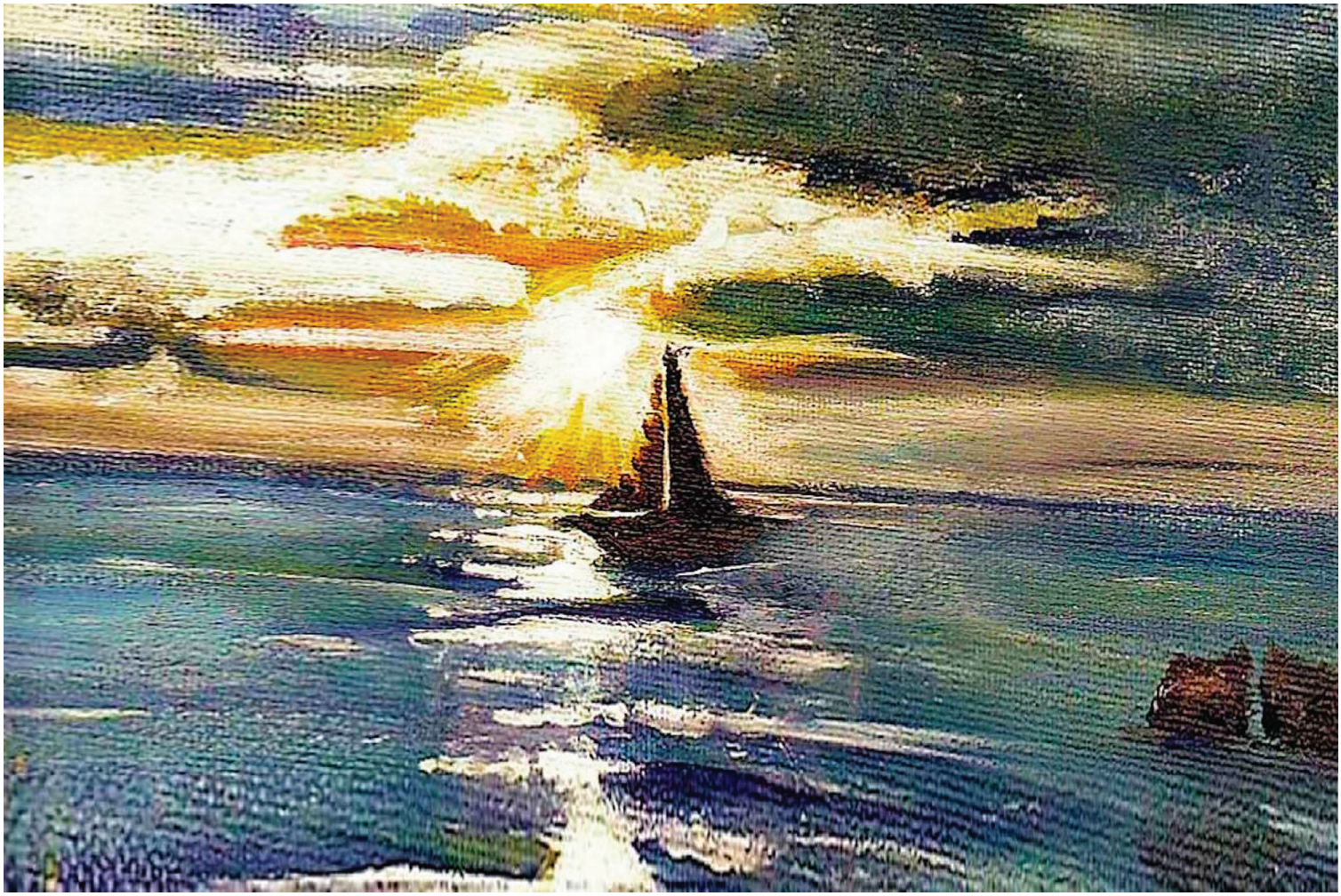

The An Saol Project

Life and Living with a Severe Acquired Brain Injury (sABI)

Proposal for a 3-year Pilot Project

(Version 1.0)

Life and Living with a Severe Acquired Brain Injury (sABI)

Proposal for a 3-year Pilot Project



Proposer: An Saol Foundation Ltd., Carmichael House, North Brunswick Street, Dublin 7
Contact: Reinhard Schaler
Tel: 087-6736414
E-Mail: reinhard.schaler@ansaol.ie

Contributors: Reinhard Schaler
Prof Andreas Bender

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PURPOSE

WE ARE A VOICE FOR THOSE WHOSE SEVERE ACQUIRED BRAIN INJURIES (SABI) HAVE SERIOUSLY CHALLENGED THEIR ABILITY TO ADVOCATE FOR THEMSELVES.

Because of dramatic improvements in emergency medicine, many more persons survive severe acquired brain injuries than ever before. While the emergency care for these injured is well understood and developed, the mid- to long-term requirements of the survivors, allowing them to construct their new lives, are not, as are the needs of the families supporting the injured.

The purpose of the proposed 3-year pilot project is the development and implementation of a framework and service supporting the life and living requirements of persons with severe acquired brain injury (sABI) and their families.

The project will be informed by best international practice and the most recent international research in relation to neurological rehabilitation following ABI (Archives of Physical Medicine and Rehabilitation, 2015). While we really don't have a good sense of what works to treat these injuries, according to the latest research, some evidence is promising. It shows that rehabilitation therapy, especially therapy that requires demanding physical or mental activity, does seem to help patients regain function.

The project will collaborate with national and international experts on neurological rehabilitation and has already identified some of these. The project will also collaborate with leading international centres providing neurological rehabilitation.

APPROACH

TO DEVELOP AND FUND A PILOT PROGRAM THAT WILL DEMONSTRATE THE BENEFITS OF EARLY AND INTENSIVE MENTAL/PHYSICAL THERAPIES, AND PROVIDE THAT TO A GROWING NUMBER OF PATIENTS WHO CURRENTLY HAVE NO ACCESS TO SUCH THERAPIES.

The project will be led by a group of experts and practitioners (Executive Council) identified by An Saol. This group will not exceed five persons.

For the purpose of the pilot, a small group of 3-5 injured will be identified as suitable candidates by the Executive Council, according to agreed criteria (type of injury, current residence, family support, etc.).

The project will offer its services in a way that is similar to that of a Day Care Centre, i.e. the project will not offer residential care, although this might be considered following the initial 3-year pilot phase. Participants will be collected from home each morning and returned home each evening.

Families of the injured will be involved via a Family Support Group.

Training and staff exchange will be organised with other suitable and interested institutions and organisations, nationally and internationally. Students and their lecturers will be invited to contribute and participate actively. A volunteer service will be developed to contribute supplementary resources (to those of the core staff).

The project will run over a period of 3 years, with yearly evaluations performed by a panel of invited international and independent experts. Following this review, the work programme will be adjusted.

Towards the end of the 3-year period and following a thorough evaluation, a plan for a longer, 5-year project will be presented, also considering the possibility of replicating the model in other parts of the country.

REHABILITATION PROGRAM

THE AN SAOL PILOT PROJECT WILL DEVELOP AND IMPLEMENT A VIABLE FRAMEWORK OF REHABILITATION AND COUNSELING SERVICES TO ASSIST THOSE AFFECTED WITH THEIR NEW CHALLENGES AND LONGER-TERM NEEDS.

Therapies will be offered to the individuals based on an asessment of their particular requirements.

Some therapies will be offered in a group setting, either in-doors (music and games) or outdoors (social interaction, dealing with situations of daily life). These therapies will be delivered primarily in the afternoon.

The professions involved in the delivery of the rehabilitation programme will include:

- Primary
    - Occupational Therapists
    - Physiotherapists
    - Speech and Language Therapists (SLT)
- Secondary
    - Facial-Oral Tract Therapy (FOTT)
    - Music Therapy
    - Neuropsychology (where adequate)

Robotic training (Erigo, Lokomat) will supplement human-delivered therapies.

Sample Timetable

There are five 40-minute morning timeslots for one/many : one tailored therapies for participants, and one two-hour group-based therapy session slot in the afternoon.

Participant 1

08:00 - 09:00	Breakfast in group
09:00 - 09:40	SLT
09:40 - 10:20	Physio
10:20 - 11:00	OT
11:00 - 11:40	Robotic Training
11:40 - 12:20	FOTT
12:20 - 14:00	Lunch Break in group
14:00 - 16:00	Group-based (social) therapies

Participant 2

08:00 - 09:00	Breakfast in group
09:00 - 09:40	SLT
09:40 - 10:20	FOTT
10:20 - 11:00	OT
11:00 - 11:40	Physio
11:40 - 12:20	Robotic Training
12:20 - 14:00	Lunch Break in group
14:00 - 16:00	Group-based (social) therapies

The rehabilitation programme will also be supported by a rehabilitation physician for adequate drugs management (only where absolutely necessary) and a neurologist.

Daily morning briefings and weekly review meetings involving relevant staff will drive and inform the treatment. Regular formal assessments and reports will document the progress of those participating.

THERAPEUTIC QUALITY CONTROL

WE HAVE SEEN DRAMATIC IMPROVEMENTS IN OUR FAMILY MEMBERS WHEN NOBODY BELIEVED THIS TO BE POSSIBLE. AND WHAT WE HAVE EXPERIENCED PERSONALLY IS SUPPORTED BY RECENT INTERNATIONAL RESEARCH WHICH SHOWS THAT DEMANDING MENTAL AND PHYSICAL ACTIVITY OFFERS THE ONLY CONSISTENTLY PROVEN MEANS TO REGAIN FUNCTION – LEADING TO A BETTER QUALITY OF LIFE.

It will be important to have a thorough initial training for therapists in order to prepare for the special therapeutic needs and concepts of long-term neurorehabilitation. This will be achieved in cooperation with 2 German institutions with longstanding experience in this field:

- Therapiezentrum Burgau, Germany
- Zentrum der Rehabilitation, Geerlofs GmbH, Pforzheim, Germany

Therapists will spend 6 weeks in the Burgau centre. A three week training course will be delivered by the Pforzheim centre in Dublin for their initial training.

With the start of the first new patients in Dublin, one member of the Burgau or the Pforzheim therapeutic team will be on site in Dublin for 4 weeks to support and supervise the team.

Throughout the three years pilot phase, additional supervision and exchange periods of 2 weeks per year per speciality (physiotherapy, occupational therapy, speech and language therapy) will be provided on site to ensure high therapeutic quality.

SCIENTIFIC APPROACH

THE PROJECT WILL BE INFORMED BY BEST INTERNATIONAL PRACTICE AND THE MOST RECENT INTERNATIONAL RESEARCH IN RELATION TO NEUROLOGICAL REHABILITATION FOLLOWING ABI.

The project will be scientifically evaluated by rehabilitation scientist from the University of Munich and other GB/IRL Universities to be determined.

Due to the low number of participants and lack of control group in this *proof-of-principle project*, no group statistics or group comparisons are advisable. Instead, success of the long-term neuro-rehabilitation approach will be determined based on reaching patient-centred individual goals.

The Goal-Attainment Scale (GAS) (Turner-Stokes 2009) will be used to identify and describe these goals at the beginning of the rehabilitation intervention and from thereon in 3-monthly intervals. At the end of such a 3 month

period, the degree of goal attainment will be determined and new goals will be set.
Goal setting will take place after careful patient evaluation by the specialised treatment team and will also take into account the point of view of the closest relatives. The international classification of Functioning, Disability and Health (ICF) by the WHO will be used as the theoretical construct of goal-setting and ICF core sets for brain injured patients will be used to describe changes in the overall patients´ health status (Stucki et al. 2002). The following table provides an overview of the different outcome domains and assessment that will be evaluated.

Table: Outcome domains and assessments to be used for longitudinal analysis of health status

Domain	Assessment instrument	Significance
Quality of life (QOL)	EuroQOL, SF-36, COLIBRI	Improvement in QOL is a major outcome factor
Participation in life	WHODAS 2.0	Analysis of limitations of participation in social and work life are important to understand effects of brain injury on patients´ lives.
Goal attainment	GAS	Scientifically proven way to make individual rehabilitation goals comparable and measurable
Caregiver strain	CSI	It is important to acknowledge the role and the strains of family caregivers
Activities of daily living (ADL)	FIM, Barthel-Index	It is a long-term rehabilitation goal to increase independence in ADLs
Limitation in health status	ICF core set for postacute brain injury	The ICF framework is suitable to measure health limitations at different time points in order to show changes in health status
Level of consciousness (LOC)	CRS-R	Many patients suffer from disorders of consciousness ranging at the beginning from unresponsive wakefulness to minimally conscious or confusional states.

It is important to have reliable and impartial assessments of the health status and rehabilitation course of the individual patients. To achieve this, independent study personnel from one of the participating universities will perform the assessments on site in Dublin at the beginning of rehabilitation and in 3 months intervals thereafter until the final pilot project assessment after 3 years. Study data will be entered into an online case-report-form (eCRF) and analysed by the University of Munich. Before patient recruitment, the appropriate institutional review board will be consulted and ethical approval will be obtained.

REQUIREMENTS

WE ARE THE FAMILIES, FRIENDS, AND SUPPORTERS OF PERSONS AFFECTED BY A SEVERE ACQUIRED BRAIN INJURY (SABI). WE HAVE ESTABLISHED THE AN SAOL FOUNDATION AND PILOT PROGRAMME TO CHANGE THE HEARTS AND MINDS OF SOCIETY TO SUPPORT SURVIVORS OF SABI, AND THEIR FAMILIES, SO THAT THEY CAN LIVE THEIR LIFE TO THE FULLEST.

Finance	A financial plan for the project is included in the Annex of this proposal. The total cost of the 3-year project are estimated at around €1.5m in total. *Note: Currently, and to our knowledge, the State pays approximately €2k per week for the care of persons with a severe acquired brain injury at home or in nursing homes, i.e. approximately €104k per annum. This does not include, at least not in all cases, additional administration and therapy costs. Thus, if 5 injured were identified, and their funding was channeled by the State into this pilot, a minimum of €1.5m would become available.*
Space	Sufficient space will be required for: • Day room with cafeteria (ca. 50m2) • Therapy room (ca. 60m2) • Office (20m2) • Toilets • A "quiet-room" for relaxation and rest. Many patients need off-time in between therapy.
Transport	A van will be required for transporting clients to and from the Centre.
Executive Council	3-5 persons to join the Executive Council will have to be identified.

Personnel	The following core staff will have to be recruited.
	• 1 Manager (part-time)
	• 1 Lead therapist (physio; full-time)
	• 3 Therapists (OT, SLT, Physio; part-time)
	• 1 Carer (full-time)
	• 1 Cook (part-time)
	• 1 Cleaner (part-time)
	• Account for frequent visits of:
	  ○ Neuropsychologists
	  ○ Rehabilitation physicians
	  ○ Neurologists
	  ○ Music therapists
	  ○ Cognitive therapists

Insurance	Appropriate insurance cover for the Centre will have to be sourced.

WORK PLAN

THE PROJECT WILL COLLABORATE WITH NATIONAL AND INTERNATIONAL EXPERTS ON NEUROLOGICAL REHABILITATION AND HAS ALREADY IDENTIFIED SOME OF THESE. THE PROJECT WILL ALSO COLLABORATE WITH LEADING INTERNATIONAL CENTRES PROVIDING NEUROLOGICAL REHABILITATION.

The work plan is organised in distinctive work packages with clearly identified deliverables as well as a schedule of work.

Work Package	Deliverable	Date
WP1 An Saol Centre Planning	Planning Report of An Saol Centre	T3
WP2 Setup	Selection of clients; recruitment and training of staff	
WP3 Operation	Operation of the Pilot Project / Centre	T4-T36
WP4 Yearly Project Reports	Yearly Centre Reports, including Scientific Reports	T12, T24, T36
WP5 Interim Project Reports	Interim Centre Reports	T6, T18, T30
WP6 Progress Reports (Injured)	Weekly progress reports	Weekly
WP7 Final Report	Final Centre Report	T36
WP8 Follow-up Project Proposal	Proposal for 5-year Follow-up Project	T32

Milestone		Date
M1	Selection of Injured	T3
M2	Opening of An Saol Centre	T4
M3	Presentation of Follow-up Plan	T30

REFERENCES

Archives of Physical Medicine and Rehabilitation. August 2015. Volume 96, Issue 8. Supplement. 173-340. What Works in Inpatient Traumatic Brain Injury Rehabilitation? Results from the TBI-PBE Study.

Stucki G, Ewert T, Cieza A: Value and application of the ICF in rehabilitation medicine. Disabil Rehabil 2002; 24: 932-8.

Turner-Stokes L: Goal attainment scaling (GAS) in rehabilitation: a practical guide. Clin Rehabil 2009; 23: 362-70.

FINANCIAL PLAN

An Saol 3-year Pilot Project Proposal 2016

Year/Quarter	Y1Q1	Y1Q2	Y1Q3	Y1Q4	Y2Q1	Y2Q2	Y2Q3	Y2Q4	Y3Q1	Y3Q2	Y3Q3	Y3Q4	Totals
Months	T1-3	T4-6	T7-9	T10-12	T13-15	T16-18	T19-21	T22-24	T25-27	T28-30	T31-33	T34-36	
Capital													
Annual rent	€60,000.00				€60,000.00				€60,000.00				€180,000.00
Maintenance (incl. heating etc.)	€10,000.00				€10,000.00				€10,000.00				€30,000.00
Other (administrative)	€10,000.00				€10,000.00				€10,000.00				€30,000.00
Travel	€10,000.00				€10,000.00				€10,000.00				€30,000.00
Car	€70,000.00				€2,000.00				€2,000.00				€74,000.00
Insurance	€20,000.00				€20,000.00				€20,000.00				€60,000.00
Equipment													
Lokomat	€200,000.00				€7,000.00				€7,000.00				€214,000.00
Erigo	€65,000.00				€3,000.00				€3,000.00				€71,000.00
MOTOMed	€4,000.00												€4,000.00
Cognitive/Communication s/w	€5,000.00												€5,000.00
Therapy Equipment	€15,000.00				€2,000.00				€2,000.00				€19,000.00
Treadmill OR Vector Gait	€100,000.00												€100,000.00
Therapeutic Quality Control													0
Initial training in Germany	€10,000.00												€10,000.00
(travel, housing)													€0.00
Supervision on site	€18,000.00				€18,000.00				€18,000.00				€54,000.00
(travel, housing, personnel)													€0.00
													€0.00
Scientific costs													€0.00
Cost for IRB approval	€1,000.00												€1,000.00
Costs for preparation eCRF	€2,000.00												
Assessments on site	€6,000.00				€6,000.00				€6,000.00				
Statistical analysis & report									€2,500.00				€2,500.00
Total Capital	€569,000.00	€0.00	€0.00	€0.00	€124,000.00	€0.00	€0.00	€0.00	€124,000.00	€0.00	€0.00	€0.00	€817,000.00
Personnel													
Manager (p/t)	€8,750.00	€8,750.00	€8,750.00	€8,750.00	€8,750.00	€8,750.00	€8,750.00	€8,750.00	€8,750.00	€8,750.00	€8,750.00	€8,750.00	€105,000.00
Lead Therapist (f/t)	€15,000.00	€15,000.00	€15,000.00	€15,000.00	€15,000.00	€15,000.00	€15,000.00	€15,000.00	€15,000.00	€15,000.00	€15,000.00	€15,000.00	€180,000.00
Therapist 1 (p/t)	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€60,000.00
Therapist 2 (p/t)	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€60,000.00
Therapist 3 (p/t)	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€60,000.00
Carer 1 (f/t)	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€60,000.00
Carer 2 (f/t)	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€5,000.00	€60,000.00
Cook (p/t)	€3,750.00	€3,750.00	€3,750.00	€3,750.00	€3,750.00	€3,750.00	€3,750.00	€3,750.00	€3,750.00	€3,750.00	€3,750.00	€3,750.00	€45,000.00
Driver (p/t)	€3,000.00	€3,000.00	€3,000.00	€3,000.00	€3,000.00	€3,000.00	€3,000.00	€3,000.00	€3,000.00	€3,000.00	€3,000.00	€3,000.00	€36,000.00
Assistant (p/t)	€2,500.00	€2,500.00	€2,500.00	€2,500.00	€2,500.00	€2,500.00	€2,500.00	€2,500.00	€2,500.00	€2,500.00	€2,500.00	€2,500.00	€30,000.00
Cleaner (p/t)	€2,375.00	€2,375.00	€2,375.00	€2,375.00	€2,375.00	€2,375.00	€2,375.00	€2,375.00	€2,375.00	€2,375.00	€2,375.00	€2,375.00	€28,500.00
Total Personnel	€60,375.00	€60,375.00	€60,375.00	€60,375.00	€60,375.00	€60,375.00	€60,375.00	€60,375.00	€60,375.00	€60,375.00	€60,375.00	€60,375.00	€724,500.00
TOTAL	€629,375.00	€60,375.00	€60,375.00	€60,375.00	€184,375.00	€60,375.00	€60,375.00	€60,375.00	€184,375.00	€60,375.00	€60,375.00	€60,375.00	**€1,541,500.00**

POTENTIAL SOURCES OF FUNDING

Health Service Executive (HSE) / Disability Services
http://www.hse.ie/eng/services/list/4/disability/

Health Research Board (HRB) / Medical Research Charities Group
http://www.hrb.ie/research-strategy-funding/open-grants-and-fellowships/mrcghrb/

COLLABORATORS AND SUPPORTERS

The following individuals and organisations will collaborate with An Saol on the development and implementation of the project in different way. They support the project and its objective to demonstrate how recent research - showing that the only proven recovery of function is intensive mental and physical exercise - can inform the practice of long-term neurological rehabilitation leading to a better quality of life and inclusion in society of those affected, of their families and friends. The level of collaboration will evolve over the lifetime of the project and could cover, amongst other areas:

- Public expressions of support
- Providing guidance and advice
- Supporting sourcing and training of employees
- Joint fundraising activities
- National and international project proposals to funding agencies

CONFIRMED

Professor Andreas Bender

Professor Bender is a neurologist and chief physician at Therapiezentrum Burgau in Germany, which has more than 25 years of experience in early inpatient rehabilitation of patients with acquired brain injury. He is also heading a neurorehabilitation research group at the University of Munich, Germany.
https://www.researchgate.net/profile/Andreas_Bender3

Acquired Brain Injury Ireland

Confirmed by Barbara O'Connell via Grainne McGettrick on 01 June 2016.
Acquired Brain Injury Ireland (ABI Ireland) is Irelands leading provider of community based neuro-rehabilitation services for people who have acquired a brain injury in Ireland.
http://www.abiireland.ie

Headway Ireland

Confirmed by Kieran Loughran, CEO, on 25 April 2016.
Headway Ireland is an internationally accredited organisation that contributes positively to the lives of people affected by brain injury, no matter who or where in Ireland.
http://www.headway.ie

Lebenszentrum Königsborn

Confirmed by CEO and Clinical Care Lead during meeting on 12 April 2016
The "Lebenszentrum Königsborn" offers children, adolescents and adults with severe neurological conditions living conditions and opportunities corresponding to their individual requirements.
http://www.lebenszentrum-koenigsborn.de/haus-koenigsborn/

Zentrum der Rehabilitation Pforzheim

Confirmed by Daniela Dorschner-Geerlofs on 12 May 2016.
The "Zentrum der Rehabilitation" are specialists in personal training for neurological clients. The most important goals of their work are the restoration of motor functions and self-reliance in patients with paraplegia and tetraplegia, traumatic brain injury, stroke, cerebral hemorrhage and other neurological disorders.
http://www.zentrum-der-rehabilitation.de

POTENTIAL

Dr. Diane Playford

Professor of Neurological Rehabilitation, University of Warwick.
Contacted. Expressed great interest in the project.
http://www2.warwick.ac.uk/fac/med/staff/dplayford/

Prof. Turner-Stokes

Director Regional Rehabilitation Unit and Dunhill Chair of Rehabilitation
Contacted
http://www.kcl.ac.uk/lsm/research/divisions/cicelysaunders/about/people/academic/turner-stokesl.aspx

Dublin City University, School of Nursing and Human Sciences

Contacted and met on 07 April 2016
http://www.dcu.ie/snhs/index.shtml

Reha-Haus Buchholz (proposed, to be confirmed)

Contacted
http://www.reha-haus-buchholz.de/

University of Limerick, Department of Computer Science and Information Systems and Department of Clinical Therapies

To be contacted

DEFINITIONS

Acquired Brain Injury (ABI)

An acquired brain injury is an injury to the brain that has occurred after birth, but is not related to congenital defect or degenerative disease. Causes of ABI include (but are not limited to) hypoxia, illness, infection, stroke, substance abuse, toxic exposure, trauma, and tumor. ABI may cause temporary or permanent impairment in such areas as cognitive, emotional, metabolic, motor, perceptual motor and/or sensory brain function.
http://www.braininjurynetwork.org/thesurvivorsviewpoint/definitionofabiandtbi.html

Severe Acquired Brain Injury (sABI)

We define a sABI as being a condition where the patient has been in an unconscious state for 6 hours or more, or a post-traumatic amnesia of 24 hours or more. We include in this group patients with very severe acquired brain injury, i.e. those which have been in a coma for 48 hours or more, or a PTA of 7 days or more. These patients are likely to be hospitalised and should receive rehabilitation once the acute phase has passed. They tend to have more serious physical deficits and will require long-term specialised neuro-rehabilitation. (See also: https://www.headway.org.uk/about-brain-injury/individuals/types-of-brain-injury/traumatic-brain-injury/how-severe-is-the-brain-injury/)

We will afford every opportunity to people with severe Acquired Brain Injury (sABI) to live their life with dignity and respect, to continue to improve, to regain as much independence and self-determination as possible, and for their injuries to heal, supported by adequate therapies.

www.ansaol.ie