

ENCALS – Who does what where?

Below can give you an idea on giving a quick overview to your colleagues from other countries - but feel free on how you do it.

Name	Muscle Centre/ALS Clinic, Kantonsspital, Haus 33, 9007 St.Gallen muskel-als@kssg.ch phone : +41 71 494 35 81, since 2006
Country	Switzerland
Habitants	8 Mio
Health System	Regulated by state, financed through a complicated mixture of private health insurances, state, county and community contributions, the insurances are obliged to take every person on basic insurance level, foederalistic structure,certain national strategies but vague national implementation rules, the 26 counties have a great deal of selfmanagement
ALS Pat.	about 600-800, no existing register and no national data collection, only international
Main Centre in CH	St. Gallen >200 ALS patients and other neuromuscular diseases
Nurses (at 100%-> 42 hrs/week)	3 persons, 80/50/40%
Consultants (1 pers., 50 hrs/week would be 100%) Neurologist	3 persons, 80/90/80% 1 person 50% (Research part from total 300% is 50%)
Admin (at 100%-> 42 hrs/week)	4 persons 170%
Close cooperation and financial support	2 Pat. Organisations: Muscle Society (financing * and gives 50'000 SFr/year to each muscle centre for nursing staff) ALS Switzerland (financing °) <u>Additional funding</u> : by patients donations, research, foundations that sponsor research, county hospital, health insurance contributions
Research	>98% of all ALS research in CH is done in St.Gallen Musclecentre/ALS Clinic
Nurses work area	<ul style="list-style-type: none"> • Assessments, study work • Care Counselling for Patients and Caregivers -Explaining ALS based on what is wished by patients and caregivers (model: motivational interviewing) • Advanced directives • Teaching of breathing techniques, assisted coughing, Heimlich manoeuvre, how to lift, use care devices • Networking, advocacy for patients and Caregivers • Emotional support (themes: narratives, orientation, hope, meaning) • Interdisc. Meetings • Cooperation with inhouse and external services (different therapists, GP, district teams) <p>Education and Training</p> <ul style="list-style-type: none"> • ALS Care Training for PwALS & CG once/year, 6 Modules, themebased, 1 afternoon each theme with ALS experienced professionals, runs its 12 th year *° • ALS Info Meetings for District Nurses and Care Homes

