Dear collaborators,

In the year that has passed since the last newsletter, a lot of things have happened. Recruiting new participants has been the main focus at most sites. The number of participants randomised has gone up from 37 to 133. Israel, Italy, and Norway have started recruiting participants. Australia, Austria, Korea and the USA have continued to recruit further participants. Brazil has continued important preparatory work, and a new team from the UK has joined the project; both countries are scheduled to start recruiting later this year. (Actually, we may even have two teams from the UK, however with some overlap in personnel.) We have also had various enquiries from researchers in other countries, but not all of them have been able to find the various resources for conducting such a complex project (yet). We continue to be extremely excited about this high level of interest from around the world.

In this newsletter, some site managers write about participants who completed the study, but some also share their experiences with participants who decided to leave the study early. The impression is that for many families, three music therapy sessions per week can be too much (probably depending on how it is organised and in what context it is offered), and parent counselling alone can be too little. I would like to take this opportunity to remind those of you who enter information into OC that there is a dedicated text box at 12 months where reasons for drop-out can be specified and explained. (In addition, please remember the important distinction between missing/not complying with some parts of the study and leaving the study completely, as discussed previously.)

Several people of the international team have contributed to disseminating information about the project. One significant event in this respect was the joint presentation at the EMTC in Oslo, which was full of the collaborative spirit and was met with enthusiasm by the audience. See some pictures here:
Also in terms of dissemination, our study was mentioned in the December 2013 newsletter of Autism Europe, a large user/advocacy organisation:
http://www.autismeurope.org/publications/newsletter-subscribe/newsletter-54/

News from the sites follow below. Thank you all for your continued enthusiasm!

Best wishes,

Christian Gold

News from the existing sites:

The Australian site reached the 5 month point with 12 families at the end of December, and has since taken a break over summer. We had some very interesting cases last year, especially with children who were older and had good verbal skills. Grace is interested in looking more closely at the music therapy processes that occurred within those sessions. Our partnership with an Autism Specialist School will continue this year, however we have had a slow start to the new school year so far - schools are busy places and it's difficult to catch Principals with time to talk. Our music therapist, Anna, will not continue with the project this year as she has moved house to a regional part of Melbourne after getting married in January. Anna did wonderful work with the children and she will be greatly missed. Grace will continue sessions with the next cohort, and hopefully we will have another music therapist on board quickly.

Grace Thompson, University of Melbourne, Australia
In Vienna, the 15th TIME-A participant just reached the end of his 5-month therapy period, which means that I can now start analysing the data of this sample of children which will be part of my PhD thesis. The 16th participant started her music therapy sessions a few weeks ago, and was the first Viennese TIME-A child who got another therapist instead of me: Agnes Burghardt-Distl, also qualified both as a music therapist and a psychologist, joined the team! Meanwhile, together with my co-authors, I’m finally in the final stages of two writing projects that are both linked to TIME-A and that have kept us busy for quite a while: the Cochrane review update on music therapy for people with ASD, and the manuscript describing the treatment guide for improvisational music therapy for children with ASD as an international consensus model. While the clinical, scientific, and site management work continues, I very much look forward to welcoming the TIME-A team here in Vienna in July. Just before our meeting and the World Congress, I will also have the opportunity to present the TIME-A project to a non-music therapy audience: The 26th annual meeting of the European Academy of Childhood Disability will be held in Vienna from July 3-5 and will include a symposium on “Evidence-based music therapy” with Thomas Hillecke, Karin Schumacher, Cochavit Elefant, and myself (see details at www.eacd2014.org).

Monika Geretsegger, Aalborg University/University of Vienna, Austria

We are happy to communicate that we have one new partner in Brazilian TIME-A: UFG University (in collaboration with the music therapist Phd. Tereza Alcântara). We bought the ADOS kit and forwarded all documentation to ADI-R and ADOS copyright permissions. Moreover we forward the SRS translation and validation to Portuguese. We had problems with WPS Company because they took a long of time to reply our e-mails. For this reason, we are waiting for more than 6 months to complete WPS copyrights requirements. Now, we have one psychologist and two music therapist in the UFRGS university team (in Porto Alegre city). In UFG we have two music therapists and we will contract one psychologist. We will just complete the copyright process with WPS to start our data collection.

Gustavo Gattino, Universidade, Federal do Rio Grande do Sul, Brazil
Israel has recently began to recruit and assess children from a new site, a center for children with Autism in Jerusalem. These children will be added to the 14 families we already have. TIME-A is very welcomed in the new center as they do not provide extra treatments for the children. The new site poses some new and interesting challenges in relation to cultural differences (ultra-religious Jews) e.g. early diagnosis, parents' counseling is not always positive and there are some elements in the ADOS that are not acceptable for this group (e.g. Looking at the book in the ADOS kit where a picture of a pig is found). Tali is no longer recruiting new children and has started to analyze the data for her PhD study on parent counseling.

*Cochavit Elefant, University of Haifa, Israel*

In Italy (Pisa and Trento) we had an intensive work as far as patients recruitment is regarded. We have enrolled eight children to the TIME-A research programme; among these children, only one dropped-out after being assigned to the control group condition. Five children have just completed five months of music therapy/counseling sessions and had their outcome evaluation. Now five more children are waiting to be randomized. The main problems regard parent difficulties in control group (parent counseling seems not so interesting) and in the high intensity condition in therapy group (it is very hard to accommodate this situation to their daily routine). Finally, we are working in order to expand TimeA creating new Time A sites in Florence and in Empoli.

*Filippo Muratori and Ferdinando Suvini, IRCCS Fondazione Stella Maris, Italy*

For total 23 children enrolled for Korean site TIME-A, 3 children completed a year course of TIME A trials. 3 drop-outs. 6 music therapy colleagues working for Korean site TIME A. Two music therapy professors with PhD in counseling doing parents' counselling sessions, and 4 music therapists MT clinical work. Three music therapists are going to join the Vienna TIME-A meeting. One music therapist recently got married, and two are going to present their own clinical work during the WCMT in Krems. I've got a new research
assistant (Freshman, soon going to be a sophomore), very intelligent, hard working student, doing OC data entry. She is such a joy to work with.

Jinah Kim, Jeonju University, Korea

Within the last months we have made big progress in Norway. Together with the psychologists and music therapists collaborating on the project, we have established good procedures for conducting the study. This helps us now to accompany ten children and their families through the project. Three music therapists have joined our research group as “field workers”. Within regular group supervision and training sessions they share their experiences with project participants and we talk about theoretical and methodological topics regarding improvisational music therapy and autism treatment in general. These sessions seem to work as perfect link between the research and the actual practice.

Within the Shared Moments project we have started with video analysis of music therapy sessions and will continue this process throughout the next years. It’s a huge amount of data and it is quite exciting to look at the video material we are collecting within TIME-A. However, before further video material can be looked at, our video data base has to be launched. After we provided the legal basis, following the EU directive concerning data transfer, we will soon be able to store all TIME-A video material on our video data base. Uni Computing has developed a data storage according to the needs of Uni Health and TIME-A will be the first project benefitting from this. A special thanks goes to Patcharee Thongtra who has done great work here. Two grant applications have been sent to the Research Council of Norway, however no funding was provided for the extended Shared Moments project we applied for.

Karin Mössler, GAMUT, Uni Research Health, Bergen, Norway

Hi all, greetings from the USA! We have a several TIME-A updates in regards to our cohorts and research projects. In regards to our TIME-A numbers, as of September 2013 to present, we have randomized 21 children. Unfortunately, we have also had 9 dropouts. It appears that the dropout rate may be due to families either unable to commit to 3 times per week of MT, or, if they were randomized to standard care, were unable to maintain their commitment to the study. In addition, we have had at least 1 family who when randomized to standard care, decided that they wanted to seek out music therapy services, thus, withdrawing from the study. Our total count includes 32 children total randomized and 11 total dropouts.
We will begin our next cohort in September, 2014. In regards to research, we have a new TIME-A sub-project underway: The Relationship between Parenting stress and Social affect in children with ASD. This new project was initiated by Psychologist, Dr. Laura B. Kestemberg, and “soon-to-be” psychologist, Laura De Gennaro, M.S. This study seeks to identify features of ASD that contribute to the levels of parenting stress in parents with children diagnosed with ASD. Thus, families coming in for the TIME-A study are asked to complete the Parenting Stress Index–4th Edition (PSI-4; Abidin, 2000). Outcomes are currently still being analyzed for interpretation. In addition, we are currently preparing to move forward with our IMCAP-ND inter-observer reliability study (using data from TIME-A), and are currently collaborating with Dr. Hia Datta from our Speech & Language Pathology Department at Molloy and City University to incorporate Electroencephalogram measures to look at brain activity as it relates to speech and auditory processing. I look forward to seeing you in Austria! (For example!)

John Carpente, Molloy College, Rockville Centre, NY, USA

News from the new sites:

Our tester is just having her ADOS research reliability training with a view to beginning tests at the end of March and we are currently recruiting a 2nd music therapist to the project. We have 20 students identified in school settings and are planning to begin the work in April. It is great to get to this stage and we are really looking forward to beginning the clinical work not to mention having fun with Open Clinica!

Amelia Oldfield, Anglia Ruskin University, Cambridge, UK

We are looking forward to joining the TIME-A study proper in August and are now in the preparation phase. We are setting up clinical work across four sites across London and the East of England. We will be recruiting researchers and therapists by May so they are inducted and ready to go by the Autumn. The main challenge is offering three times a week ... at this point we are still optimistic! Very keen to see if there is a difference in dosage. Do not want to miss the unique opportunity to test it.

Anna Maratos, CNWL Foundation NHS Trust, London, UK

Special news from the central office:
Dear all, the last 10 months has passed very quickly. During this period a lot of issues were changes as well as my life. My daughter, Antonia was born 21.06.2013 and she turned my world upside down. I would like to thank you for very nice welcoming from my maternity leave. I’m very glad to be involved in TIME-A project. Project is going on very well. OC looks very impressive. This is the merit of all of us! I warmly welcome the persons from UK sites (Cambridge and London): Anna, Mike, Helen, Orla, Amelia. Congratulation for Karin and Ferdinando for starting the study on yours site, John for IMCAP-ND, all of you for a lot of yours achievements and success as well. I’m looking forward to seeing you in next TIME-A meeting in Vienna. Thank you for help with preparing the next Newsletter!

Łucja Bieleninik, GAMUT, Uni Research Health, Bergen, Norway