EPSSG ASSOCIATION

THE EUROPEAN PAEDIATRIC SOFT TISSUE SARCOMA STUDY GROUP

ANNUAL REPORT 2017

THE EPSSG ASSOCIATION

The European Paediatric Soft tissue sarcoma Study Group (EpSSG) is an international organisation for professionals devoted to the care and treatment of children and young people with cancers known as soft tissue sarcoma (STS). This includes the most common STS, rhabdomyosarcoma (RMS), and a wide range of other cancers known collectively, as Non Rhabdomyosarcoma Soft Tissue Sarcomas (NRSTS).

The legal entity for EpSSG activities is the EpSSG Association. This exists to promote and manage clinical trials, encourage and facilitate clinical and basic science research, foster optimal standards of care, organise educational meetings for its members and other professionals, and advocate for patients with STS.

It collaborates with other similar groups in Europe, North America and elsewhere.

EpSSG has its administrative and legal home in Padua, Italy. It is managed by an elected board, and its membership is open, by application, to professionals who have an interest in the research or treatment of these diseases when they occur in teenagers and young adults.

This report summarises the main EpSSG activities that have been developed in 2017. Importantly, we have had the opportunity to welcome parents of sarcoma patients to collaborate with us and support the development of our activities since 2016.

Further information is available on the EpSSG website: www.epssgassociation.it

EpSSG Board

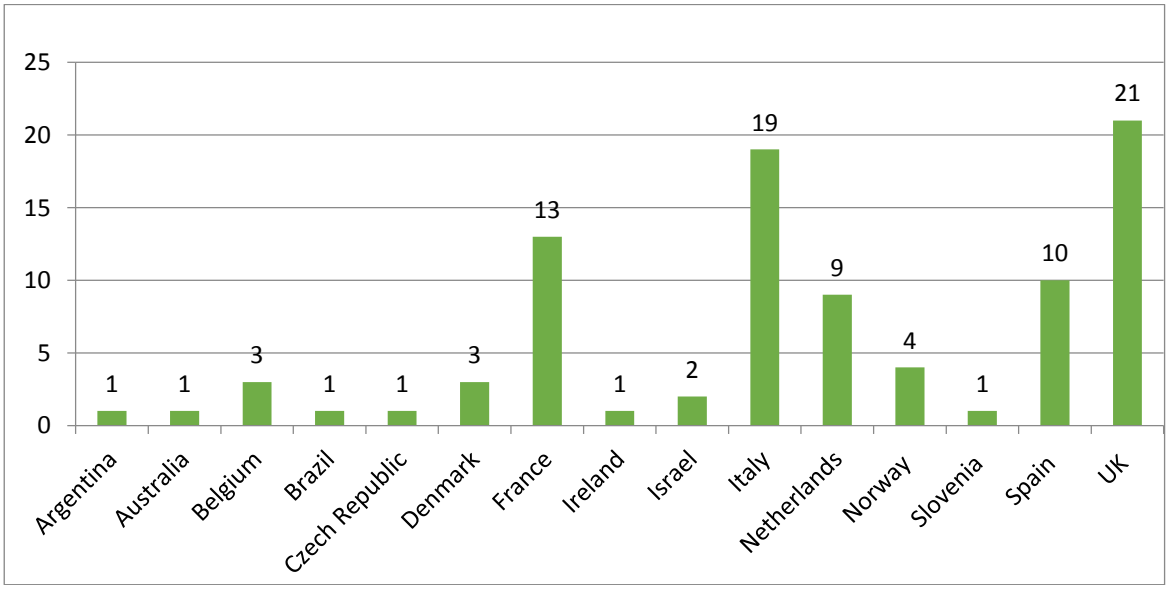
Prof. Gianni Bisogno	•Chairman - Padua, Italy
Dr. Christophe Bergeron	•Lyon, france
Dr. Julia Chisholm	•Sutton, United Kingdom
Dr. Andrea Ferrari	•Milan, Italy
Dr. Soledad Gallego	•Barcelona, Spain
Dr. Heidi Glosli	•Oslo, Norway
Dr. Meriel Jenney	•Cardiff, United Kingdom
Dr. Hans Merks	•Treasurer - Amsterdam, The Netherlands
Dr. Daniel Orbach	•Paris, France

Board meetings were held on the following dates in 2017:
March 13th, May 10th, October 2nd, December 3rd, 5th.
TCs were held on: June 21st, July 11th, September 12th.

EpSSG membership

EpSSG studies are undertaken in the following countries: Italy, France, UK, The Netherlands, Spain, Belgium, Ireland, Denmark, Norway, Czech Republic, Slovenia, Israel, Argentina, Brazil. Each country has an EpSSG National Coordinator.

In 2017 there were 93 individual members of the EpSSG from 15 different countries.



EpSSG Subcommittees

	Chair
Biology	Prof Janet Shipley, Sutton, UK
Pathology	Dr Anna Kelsey, Manchester, UK
Radiology	Prof Rick R. van Rijn, Amsterdam, The Netherlands
Surgery	Dr Timothy Rogers, London, UK
Radiotherapy	Dr Henry Mandeville, Sutton, UK
Phase I/II trials	Dr Michela Casanova, Milan, Italy
Biostatistics/Data management	Dr Gian Luca De Salvo, Padua, Italy

EpSSG Meetings 2017

The Spring meeting took place on 10th -11th May 2017 at the IDA Conference Centre, in Copenhagen, Denmark The meeting was hosted by Dr Catherine Rechnitzer, the meeting included discipline panel meetings on surgery, biology-pathology, Phase II, Radiotherapy, and a FAR-RMS update and International Symposium: "Focus on Precision Medicine in Soft Tissue Sarcomas".

The winter meeting took place the 4 th - 5th of December at the Centre Léon Bérard, Lyon, France. It was hosted by Dr Nadege Corradini and included discipline panel meetings on biology, radiotherapy, NRSTS TMC, Surgery, Pathology, Phase II, Radiology, and an International Symposium on "Malignant Peripheral Nerve Sheath Tumors" (MPNSTs) has been held.

The New **F**rontline **a**nd **R**elapse study in **R**habdo**M**yo**S**arcoma (FaR-RMS) has now been funded in Several countries across the EpSSG. It is an overarching study for patients with both newly diagnosed and recurrent RMS and is open to patients of all ages. The Study is coordinated through the Cancer Research Clinical Trials Unit in Birmingham UK and is due to open to recruitment in the autumn of 2018.

PARENTS AND EpSSG

PARENTS AND EpSSG 2017 DR. JULIA CHISHOLM AND ANGELIKA SANDAKLY

We welcomed four parents, including a local parent from Copenhagen, to the Spring meeting in May 2017 and four parents to the Winter meeting in December 2017, including parents of a child being treated in Lyon. Thus to date 6 parents have been involved in EpSSG meetings.

It was encouraging that parents found more opportunity to contribute in the main meeting in December 2017. The Board had an opportunity to meet with the parents at the end of each meeting to obtain feedback and discuss the way forward. After the December meeting there was general agreement of the value of a parents group and those parents involved have now created a WhatsApp group to provide ongoing communication and support.

The aim is eventually to include a parent from each EpSSG country who can provide liaison with other national parents and with the EpSSG board. The first projects to work on are the creation of a "Parents Corner" on the EpSSG website and review of the parent information sheets for the FaR-RMS study, which is due to open in 2018.

From a parent's point of view:

Firstly, let me say thank EpSSG, for the opportunity that we had by attending the last meetings: to get an insight in your work and to take over a small role in the association.

Right after our last meeting in Lyon we started our WhatsApp group with an ambiguous schedule with some tasks for the otherwise busy month of December to give birth to the ideas which emerged from our discussion.

As a first result we have a draft with an intro and a structure for the parent's portal. This is an excellent starting point for further discussions.

In the French patients group *InfoSarcomes* we worked on a set of video interviews on family experiences which might be made available to a larger public if we manage to get them translated and to overcome some technical issues.

We are looking forward to enlarging our activities to turn our personal experience into something beneficial for EpSSG and its public. It's good to know that our contribution might be useful for your work, it's a very small give back for the efforts you do for our children.

We'll be happy to review the parent related papers for the FaR – RMS study as soon as we can be involved in the ongoing work.

REPORTS FROM TRIAL COMMITTEES PROF. GIANNI BISOGNO /DR. GIAN LUCA DE SALVO

a) RMS 2005
This is the first International EpSSG trial for children and adolescents with localized rhabdomyosarcoma. Patients are included in 4 different risk groups according to 6 prognostic factors (result of initial surgery, histology subtype, tumour site and size, nodal involvement and patient age). Overall, 1762 patients were enrolled from 134 centres in 14 countries.

Low risk Group
74 patients were enrolled and treated with vincristine and actinomycin D for 22 weeks. Results are very satisfying with 3-year Event Free Survival (EFS) of 93.4% (CI95% 83.3-97.5) and 3-year Overall Survival (OS) of 100%.

Standard risk group
612 patients were enrolled and treated with ifosfamide, vincristine and actinomycin D (IVA) but with a higher ifosfamide cumulative dose if patients had not received radiotherapy . The analysis of the results obtained in the different subgroups is underway.

High Risk Group
Patients were eligible to be included in 2 consecutive randomized trials. In the 1st trial 484 patients were randomized to receive ifosfamide, actinomycin D and vincristine with or without doxorubicin given in the first 4 courses: no benefit from the addition of doxorubicin was documented. In the second trial 371 patients in complete remission after 9xIVA cycles have been randomised to stop treatment or to continue with low dose maintenance therapy with a combination of cyclophosphamide and vinorelbine. Initial analysis showed promising results and the analyses are now being finalised.

Very High Risk Group
139 patients with alveolar RMS and nodal involvement were included in this group: 3-year EFS and OS were 54.6 (CI95% 45.1-63.1) and 68.8 (CI95% 53.4-76.4), respectively.

Overall, the EpSSG RMS2005 trial showed an improvement in survival for patients with RMS when compared with previous European experiences. This study has been submitted for publication.

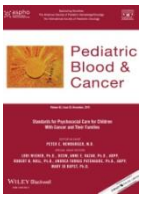
NRSTS 2005 DR. ANDREA FERRARI

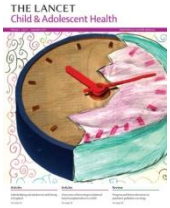
After the publication of the series on synovial sarcoma, infantile fibrosarcoma, and extracranial malignant rhabdoid tumours, the EpSSG NRSTS Committee continued the analysis of selected series of NRSTS histotypes.

In the last year, two new series were published (on alveolar soft part sarcoma and desmoid-type fibromatosis).

Further analyses are ongoing.

PUBLISHED PAPERS IN 2017





1. **ACCESS TO CLINICAL TRIALS FOR ADOLESCENTS WITH SOFT TISSUE SARCOMAS: ENROLLMENT IN EUROPEAN PEDIATRIC SOFT TISSUE SARCOMA STUDY GROUP (EPSSG) PROTOCOLS.** Pediatr Blood Cancer. 2017 Jun;64(6).

Ferrari A, Trama A, De Paoli A, Bergeron C, Merks JHM, Jenney M, Orbach D, Chilshom JC, Gallego S, Glosli H, De Salvo GL, Botta L, Gatta G, Bisogno G /RARECAREnet Working Group

-This report compares the number of adolescents (15–19-year-olds) and children (0–14-year-olds) enrolled in the protocols of the European pediatric Soft tissue sarcoma Study Group (EpSSG) with the number of cases expected to occur.
- The observed cases included patients enrolled in any of the EpSSG protocols from October 2008 to October 2015, when all EpSSG protocols were open in Italy, France, Spain, the Netherlands, United Kingdom, and Ireland. 2,118 cases aged 0–19 years were enrolled in the EpSSG: 82.8% were children and 17.2% were adolescents.
- The observed-to-expected (O/E) ratio was detected in the EpSSG countries: 0.30 among patients 15–19 years old, as opposed to 0.64 for those 0–14 years old. It differed for the different subtypes: in adolescents, it was 0.64 and 0.18 for rhabdomyosarcoma (RMS) and non-rhabdomyosarcoma soft tissue sarcomas (NRSTS), respectively; in children, it was 0.77 and 0.50, respectively.
Conclusions: Adolescents were less well represented than children on the EpSSG protocols, with better enrolment for RMS than for NRSTS for all age groups.

2. **SURGERY ALONE IS SUFFICIENT THERAPY FOR CHILDREN AND ADOLESCENTS WITH LOW-RISK SYNOVIAL SARCOMA: A JOINT ANALYSIS FROM THE EUROPEAN PAEDIATRIC SOFT TISSUE SARCOMA STUDY GROUP AND THE CHILDREN'S ONCOLOGY GROUP**. Eur J Cancer. 2017 Apr 6;78:1-6.

Ferrari A, Chi YY, De Salvo GL, Orbach D, Brennan B, Randall RL, Mc Carville MB, Black JO, Alaggio R, Hawkins DS, Bisogno G, Spunt SL.

-This analysis pooled data from the two prospective clinical trials to assess outcomes in SS patients treated with a surgery-only approach and to identify predictors of treatment failure.
- Sixty patients under 21 years of age were eligible for the analysis; 36 enrolled in the COG (from 2007 to 2012) and 24 in the EpSSG study (from 2005 to 2012). The 3-year event-free survival was 90% (median follow-up 5.2 years, range 1.9e9.1). All eight events were local tumour recurrence, whereas no metastatic recurrences were seen. All patients with recurrence were effectively salvaged, resulting in 100% overall survival.
Conclusion: This joint prospective analysis showed that patients with adequately resected 5 cm SS, regardless of grade, can be safely treated with a surgery-only approach. Avoiding the use of adjuvant chemotherapy and radiotherapy in this low-risk patient population may decrease both short- and long-term morbidity and mortality.

3. **OPEN-LABEL, MULTICENTRE, RANDOMISED, PHASE II STUDY OF THE EPSSG AND THE ITCC EVALUATING THE ADDITION OF BEVACIZUMAB TO CHEMOTHERAPY IN CHILDHOOD AND ADOLESCENT PATIENTS WITH METASTATIC SOFT TISSUE SARCOMA (THE BERNIE STUDY).** Eur J Cancer. 2017 Sept 83:177–184.

Chisholm J, Merks JHM, Casanova M, Bisogno G, Orbach D, Gentet JC, Thomassin-Defachelles AS Chastagner P, Lowis S, Ronghe M, Mc Hugh K, Van Rijn RR, Hilton M, Bachir J, Fürst-Recktenwald S, Geoerger B, Oberlin O the (EpSSG) and the European Innovative Therapies for Children with Cancer (ITCC)

-We evaluated the role of bevacizumab as part of the multi-modality treatment of children and adolescents with metastatic rhabdomyosarcoma (RMS) or non-rhabdomyosarcoma soft tissue sarcoma (NRSTS).
-Eligible patients aged ≥6 months to <18 years were randomised to receive induction chemotherapy (four cycles of IVADo + five cycles of IVA, ±bevacizumab), surgery and/or radiotherapy, followed by maintenance chemotherapy (12 cycles of low-dose cyclophosphamide + vinorelbine, ±bevacizumab). One hundred and fifty-four patients were randomised to receive chemotherapy alone (n = 80) or with bevacizumab (n = 74).
-At the data cut-off for the primary efficacy analysis, median EFS was 14.9 months (95% confidence interval [CI]: 10.8–35.9) with chemotherapy and 20.6 months (95% CI: 15.2–24.9) with bevacizumab plus chemotherapy (stratified hazard ratio [HR] = 0.93; 95% CI: 0.61–1.41; P = 0.72). The HR for EFS in patients with RMS (n = 103) was 1.24 (95% CI: 0.73–2.09) versus 0.64 (95% CI: 0.32–1.26) for those with NRSTS (n = 49). Objective response rate was 36.0% (95% CI: 25.2–47.9) with chemotherapy and 54.0% (95% CI: 40.9–66.6) with bevacizumab plus chemotherapy (difference of 18.0%; 95% CI: 0.6–35.3).
Conclusion: The addition of bevacizumab to chemotherapy appeared tolerable in children and adolescents with metastatic RMS/NRSTS, but the primary end-point of EFS did not show statistically significant improvement.

4. **DESMOID TUMORS IN CHILDREN: THE EXPERIENCE OF THE EUROPEAN PEDIATRIC SOFT TISSUE SARCOMA STUDY GROUP (EPSSG) – NRSTS 05 STUDY – AN INTERNATIONAL PROSPECTIVE CASE SERIES.** Lancet Child & Adolescent Health 1: 284–92, 2017

Orbach D, Brennan B, Bisogno G, Van Noesel M, Minard-Colin V, Daragjati J, Casanova M, Corradini N, Zanetti I, De Salvo GL, Defachelles AS, Kelsey A, Ben Arush M, Francotte N, Ferrari A.

-In 2005, the EpSSG proposed a conservative treatment algorithm—consisting of an initial wait-and-see strategy, non-mutilating surgery, and minimal-morbidity chemotherapy (in the case of tumour progression)—for paediatric patients with desmoid-type fibromatosis.
-From Oct 1, 2005, to July 31, 2016, 173 patients were registered from 57 centres in 8t countries: 35% patients had no immediate therapy (wait-and-see strategy), 31% had immediate surgery, and 34% had immediate chemotherapy after diagnosis.
-5-year PFS was 36·5% overall, 26·7% in the wait-and-see group, 41·2% in the surgery group, and 42·8% in the chemotherapy group (overall log-rank p=0·1)7.
-In multivariable analysis, large tumour size (>5 cm) was associated with worse PFS. Apart from one patient in the chemotherapy group who died from a secondary tumour, all patients were alive at the time of analysis. Overall, 8% patients had biopsy only (no further treatment), 42% had chemotherapy only, 20% had surgery only, 23% had both chemotherapy and surgery, and 6% had radiotherapy in addition to other therapies.
-In conclusion, in paediatric patients with desmoid-type fibromatosis, the EpSSG conservative strategy did not compromise outcomes and could be adopted to reduce treatment burden.

5. **ALVEOLAR SOFT PART SARCOMA IN CHILDREN AND ADOLESCENTS: THE EUROPEAN PAEDIATRIC SOFT TISSUE SARCOMA STUDY GROUP PROSPECTIVE TRIAL (EPSSG NRSTS 2005).** . Pediatr Blood Cancer. 2017 Dec 29. doi: 10.1002/pbc.26942

Brennan B, Zanetti I, Gallego S, Francotte N, Van Noesel M, Kelsey A, Casanova M, De Salvo GL, Bisogno G, Ferrari A

-22 patients with ASPS were enrolled into the EpSSG NRSTS 2005 study. After surgical resection, subsequent treatment depended on the stratification of patients for IRS) stage, size, and grade. Chemotherapy using ifosfamide and doxorubicin was performed in IRS group III. Radiotherapy was performed in IRS groups II and III, and grades 2 and 3 tumors.

-The majority in the series had localized disease (20 cases), with small IRS I tumors (12 cases), and in total 19 had surgical resection upfront. Of the four patients who received conventional chemotherapy, there were no responses. Concerning the outcome, 3/20 patients with localized tumors and all metastatic patients developed metastases. The 5-year EFS of patients with localized disease is 94.7% and the OS is 100%.

-In conclusion, this report demonstrates the ability to run prospective pediatric studies in NRSTS in multiple European countries, despite the small numbers of ASPS patients. We can conclude that for the majority with small resected tumors, there were few events and no deaths.

6. **GENOMIC COMPLEXITY IN PEDIATRIC SYNOVIAL SARCOMAS (SYNOBIO STUDY): THE EUROPEAN PEDIATRIC SOFT TISSUE SARCOMA GROUP (EpSSG) EXPERIENCE** Cancer Med. 2018 Mar 13. doi: 10.1002/cam4.1415

Orbach D, Mosseri V, Pissaloux D, Pierron G, Brennan B, Ferrari A, Chibon F, Bisogno G, De Salvo GL, Chakiba C, MD, Corradini N, Minard-Colin V, Kelsey A,Ranchère-Vince D.

-A genomic index (GI) tool using array comparative genomic hybridization (aCGH) on tumor cells has emerged as independent prognostic factor associated with the risk of metastatic relapse in synovial sarcoma. The aim of this tudy was to assess GI in pediatric patients with SS, to determine its value as a prognostic factor.

-61 patients <25 years) with localized SS prospectively included in the European EpSSG-NRSTS05 protocol with a contributive aCGH were selected.

-Definition of GI was A^2/C, where A is the total number of alterations (segmental gains and losses) and C is the number of involved chromosomes on aCGH results.

-GI1 group corresponds to cases with no copy number alterations (flat profile, GI=0) and GI2 group cases with at least one or more copy number alterations (rearranged profile; GI≥1).

-Overall, 55.7% were GI1 group, and 44.3% GI2. Respectively for GI1 vs. GI2 groups, 5-year EFS were 93.8 vs. 64.9 (P<0.006) and 5-year-MFS 93.8 vs. 72.9 (P<0.04). In multivariate analysis, GI status as adjusted for IRS group, patient age, site and tumor size remains independent prognostic for EFS with a relative risk (RR) of 6.4 (p<0.01) and for MFS with a RR of 4.8 (p<0.05).

-In conclusions, genomic complexity evaluated through GI may explain the metastatic behavior of pediatric SS.

EARLY PHASE TRIALS DR. MICHELA CASANOVA

BERNIE

The BERNIE study was a joint EpSSG/ITCC randomized phase II study of standard chemotherapy +/- bevacizumab in paediatric metastatic soft tissue sarcoma, sponsored by F Hoffman la Roche.

The results of the study were published on Eur J Cancer (Chisholm JC, Merks JHM, Casanova M, et al; "*Open-label, multicentre, randomised, phase II study of the EpSSG and the ITCC*

evaluating the addition of bevacizumab to chemotherapy in childhood and adolescent patients with metastatic soft tissue sarcoma (the BERNIE study)". **Eur J Cancer** 2017 Sep; 83:177-184).

In collaboration with the Radiotherapy EpSSG Committee, additional analysis on the role of radiotherapy in metastatic patients were performed in RMS patients enrolled in BERNIE and presented at ASCO 2017 and SIOP 2017. A separate paper on the NRSTS patients in collaboration with the NRSTS EpSSG Committee is planned.

VIT 0910

The VIT 0910 study (randomised phase II study of vincristine and irinotecan (VI) +/- temozolomide (T) in refractory/relapsed RMS) is a joint ITCC/EpSSG investigator initiated study sponsored in Lille, France.

The Principal Investigator is Dr Anne-Sophie Defachelles. The study open in France, UK, Italy, the Netherlands and Spain, enrolled 119 patients by the end of 2017 (missing only 1 patient to the target accrual of 120 patients).

Because of the promising early results, the comparison of VI with VIT will be continued from the VIT 0910 study as a phase III question within FaR-RMS in relapsed patients to allow assessment of the impact of temozolomide on the primary endpoint of EFS.

REGORAFENIB

The phase 1b expansion cohort to evaluate safety and tolerability of regorafenib combined with vincristine/irinotecan (VI) in patients with relapsed/refractory RMS and other solid tumors was introduced as an amendment in the regorafenib pediatric Phase 1 study, sponsored by Bayer. This study resulted from a very positive discussion over the year between the company and the academic parties (ITCC and EpSSG). The enrollment will start early 2018.

The early phase trials committee continues to work with pharma and the EpSSG Biology Committee to facilitate the access to new agents for the FaR-RMS trial and other indications. In particular there is an agreement with Bayer that if the combination of regorafenib and VI will be feasible and tolerable, it will be incorporated in the relapsed randomized phase II study part of FaR-RMS. There are ongoing efforts on the proposal to include volasertib in FaR-RMS.

During the recent SIOP congress 2017 the following abstracts were presented by EpSSG members:

1. REVISITING RISK STRATIFICATION IN PATIENTS WITH LOCALIZED RHABDOMYOSARCOMA (RMS): A REPORT FROM THE EUROPEAN PAEDIATRIC SOFT TISSUE SARCOMA STUDY GROUP (EPSSG)

G. Bisogno, M. Jenney, S. Gallego, C. Bergeron, J.H. Merks, J. Chilsom, A. Ferrari, Z. Angelica, H. Martelli, A. Kelsey, H. Glosli, V. Minard Colin, M. Ben-Arush, I. Zanetti, G.L. De Salvo

2. DOES EARLY DETECTION WITH OFF-THERAPY SURVEILLANCE IMAGING IMPROVE SURVIVAL IN PEDIATRIC RHABDOMYOSARCOMA PATIENTS? THE EUROPEAN EXPERIENCE

B. Vaarwerk, C. Mallebranche, M.R. Adams, M. Jenney, M. C. Affinita, G. Bisogno, K. McHugh, R. R. van Rijn, D. Orbach, J. H.M. Merks.

3. OUTCOME OF PATIENTS WITH GROUP I EMBRYONAL RHABDOMYOSARCOMA IN THE EPSSG RMS 2005 STUDY.

C. Bergeron, M. Jenney, S. Gallego, J.H.M. Merks, H. Glosli, A. Ferrari, D. Ranchère -Vince, T. Rogers, V. Minard-Colin, J. Chisholm, GL De Salvo, G. Bisogno.

4. MALIGNANT PERIPHERAL NERVE SHEET TUMORS (MPNST) IN CHILDREN AND ADOLESCENTS: REPORT OF THE EUROPEAN PEDIATRIC SOFT TISSUE SARCOMA GROUP (EPSSG) NRSTS-2005 STUDY

M.M. van Noesel, D. Orbach, B. Brennan, GL De Salvo, I. Zanetti, N. Francotte, R. Alaggio, A. Kelsey, G.Bisogno, M. Casanova, A. Ferrari

5. GENOMIC INDEX IN PEDIATRIC SYNOVIAL SARCOMA (SYNOBIO STUDY), FINAL RESULTS: THE EUROPEAN PEDIATRIC SOFT TISSUE SARCOMA GROUP (EpSSG) EXPERIENCE

D. Orbach, V. Mosseri, D. Pissaloux, B. Brennan, A. Ferrari, F. Chibon, G. Bisogno, G.L. De Salvo, C. Chakiba6, N. Corradini, V. Minard-Colin, A. Kelsey, D. Ranchère-Vince

6. OUTCOME OF LOCALIZED LIVER-BILE DUCTS RHABDOMYOSARCOMA ACCORDING TO LOCAL THERAPY. A REPORT FROM THE EUROPEAN SOFT TISSUE SARCOMA GROUP (EPSSG) RMS 2005 STUDY

F. Guerin, G. Cecchetto, T.N. Rogers, S. Terwisscha Van Scheltinga, G. Guillen Burrieza, V. Minard-Colin, H. Mandeville, A. Kelsey, G.L. De Salvo, G. Bisogno, H. Martelli

7. ROLE OF RADIOTHERAPY TO PRIMARY/METASTATIC SITES IN PEDIATRIC PATIENTS WITH METASTATIC RHABDOMYOSARCOMA IN THE BERNIE STUDY.

A. Cameron, J. Chisholm, M. Elze, M. Casanova, B. Geoerger, M. Gaze, O. Oberlin, J. Bachir, S. Furst-Rechtenwald, J.H.M. Merks.

During the recent ASCO meeting 2017 the following abstracts were presented by EpSSG members

1. GENOMIC INDEX IN PEDIATRIC SYNOVIAL SARCOMA (SYNOBIO STUDY): THE EUROPEAN PEDIATRIC SOFT TISSUE SARCOMA GROUP (EpSSG) EXPERIENCE.

D. Orbach, V. Mosseri, D. Pissaloux, B. Brennan, A. Ferrari, F. Chibon, G. Bisogno, G.L. De Salvo, C. Chakiba, N. Corradini, V. Minard-Colin, A. Kelsey, D. Ranchère-Vince. J Clin Oncol 35, 2017 (suppl; abstr 10529).

2. ROLE OF RADIOTHERAPY TO PRIMARY/METASTATIC SITES IN PEDIATRIC PATIENTS WITH METASTATIC RHABDOMYOSARCOMA IN THE BERNIE STUDY.

Cameron A, Chisholm J, Elze MC, Casanova M, Geoerger B, Gaze M, Oberlin O, Bachir J, Furst-Reckenwald S, Merks JH.

FINANCIAL STATEMENT 2017 DR. J.H.M. MERKS

Total income for the association in 2017 was €5.600, mainly from members' fees and meeting registration. Interest on accounts and investments was €500,00

Total expenses were €20.668; Secretary salary (€13.728,00) annual and Board meeting costs (€4.000,00) accountant's costs (€761,00) Auditor costs (€1.268,00) and financial advice costs (€160,00), bank costs (€250,00) and passive contingencies (€500,00).

€9.000 was placed in the new EpSSG bank account (this has been done to save guard the interest of the EpSSG funds due to Italian Law that does not guarantee bank liquidity after €100.000 in account).

For 2018 we expect income from EpSSG membership fees and meeting fees from our Spring and Winter meetings; we aim to negotiate with Pharma whenever we substantially invest our expertise and network into Paediatric Investigation Plans or other work. As our association is vital to maintain both expertise and the clinical network this justifies financial support from parties that need substantial input from EpSSG (members).

An accountancy report was presented during the EpSSG general assembly held at the Copenhagen spring meeting in 2017. A Treasurer's Report of the final year's accounts was presented and approved during the EpSSG Winter meeting held in Lyon 2017.

Funding Sources: The EpSSG is indebted to the Kick Cancer Foundation, founded by one of our parents, Delphine Heenen, for supporting a new EpSSG data manager and for supporting preclinical pilot research directly supporting the biological studies planned within the EpSSG FaR-RMS study

WORKPLAN IN 2018

1. Increased communication with members through the use of our EpSSG newsletters and emails, increased networking time at meetings.
2. Enhanced EpSSG Subcommittee activities and involvement
3. "Maintaining a constant and programmed" data delivery from the International data Centre
4. Increased and consolidated EpSSG analysis (IDC) and publications
5. 3rd EpSSG Report: finalize and share Report 2017
6. New FaR RMS protocol: prepare for the launch of the new protocol in 2018
7. Funds for EpSSG projects
8. Increased EpSSG collaboration with Parents: gathered ideas for a "Parents corner" to be setup in the New EpSSG Website.

Help support the EpSSG Association

WE HAVE A DONATION BUTTON ON OUR WEBSITE! HELP US SPREAD THE WORD!

The EpSSG coordinates European international clinical trials aimed at improving the treatment of soft tissue sarcoma (STS). Through research our goal is to improve the quality of care offered to children, teenagers and young adults with STS and to improve the outcomes of treatment.

Your donation will help to support the team of clinicians, scientists, statisticians and data managers in developing and running new clinical trials in paediatric STS in order to help future generations of children with STS.

photograph taken by dr. Andrea Ferrari

Association meetings - Calendar 2017-2019

DATE	MEETING	LOCATION	NOTES
2017			
May 11-12 (Th-Fri)	EpSSG Spring Meeting & Association Assembly	Copenhagen Local organizer Catherine Rechnitzer	PERFORMED
December 4-5 (Mo-Tu)	EpSSG Winter Meeting & Association Assembly	Lyon Local organizer: Christophe Bergeron	PERFORMED
2018			
May 10-11 (Th-Fr)	EpSSG Spring Meeting & Association Assembly	Oslo Local organizer: Heidi Glosli	CONFIRMED
December 6-7 (Th-Fr)	EpSSG Winter Meeting & Association Assembly	Utrecht	CONFIRMED
2019			
May 20-25 (Mo-Sat)	EpSSG Spring Meeting & Association Assembly	SIOPE Congress	CONFIRMED
December 5-6 (Th-Fr)	EpSSG Winter Meeting & Association Assembly	London	CONFIRMED