Update from the Working Group on Adult Congenital Heart Disease

J.W. Roos-Hesselink (Chairperson)

August 2019
Summary

➢ Name change
➢ Nucleus composition
➢ Membership
➢ Congresses & Meetings
➢ Research & publication
➢ 2020 Elections
Name change

**GUCH**
- No longer appropriate
- Refers to adolescents up to the age of 25

**ACHD**
- Widely adopted internationally
- Better covers the patients and disease entities
## Nucleus 2018-2020 composition

<table>
<thead>
<tr>
<th>Nucleus Member Role</th>
<th>Start mandate</th>
<th>End mandate</th>
<th>First Name</th>
<th>Last Name</th>
<th>Country of Work</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chairperson</td>
<td>01/09/2018</td>
<td>31/08/2020</td>
<td>Jolien W</td>
<td>Roos-Hesselink</td>
<td>Netherlands</td>
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<tr>
<td>Vice-Chairperson</td>
<td>01/09/2018</td>
<td>31/08/2020</td>
<td>Gerhard Paul</td>
<td>Diller</td>
<td>Germany</td>
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<tr>
<td>Past-Chairperson</td>
<td>01/09/2018</td>
<td>31/08/2020</td>
<td>Werner</td>
<td>Budts</td>
<td>Belgium</td>
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<tr>
<td>Treasurer</td>
<td>01/09/2018</td>
<td>31/08/2020</td>
<td>Harald Mario</td>
<td>Gabriel</td>
<td>Austria</td>
</tr>
<tr>
<td>Secretary</td>
<td>01/09/2018</td>
<td>31/08/2022</td>
<td>Oktay</td>
<td>Tutareil</td>
<td>Germany</td>
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<tr>
<td>Web Editor</td>
<td>01/09/2018</td>
<td>31/08/2022</td>
<td>Laura</td>
<td>Dos Subira</td>
<td>Spain</td>
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<tr>
<td>Ordinary nucleus member</td>
<td>01/09/2018</td>
<td>31/08/2022</td>
<td>Michael</td>
<td>Gatzoulis</td>
<td>United Kingdom</td>
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<tr>
<td>Ordinary nucleus member</td>
<td>01/09/2016</td>
<td>31/08/2020</td>
<td>Pastora</td>
<td>Gallego Garcia De Vinuesa</td>
<td>Spain</td>
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<tr>
<td>Ordinary nucleus member</td>
<td>01/09/2018</td>
<td>31/08/2022</td>
<td>Margarita</td>
<td>Brida</td>
<td>Croatia</td>
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<td>01/09/2016</td>
<td>31/08/2019</td>
<td>Markus</td>
<td>Schwerzmann</td>
<td>Switzerland</td>
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<td>De Backer</td>
<td>Belgium</td>
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<tr>
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<td>31/08/2020</td>
<td>Alessandro</td>
<td>Giamberti</td>
<td>Italy</td>
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<tr>
<td>Affiliated Members</td>
<td>01/09/2018</td>
<td>31/08/2020</td>
<td>Gary D</td>
<td>Webb</td>
<td>United States of America</td>
</tr>
<tr>
<td>Affiliated Members</td>
<td>01/09/2018</td>
<td>31/08/2020</td>
<td>Massimo</td>
<td>Chessa</td>
<td>Italy</td>
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</tbody>
</table>

Contact the nucleus members [online here](#)
Membership

Evolution since 2010

<table>
<thead>
<tr>
<th>Year</th>
<th>Membership</th>
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</thead>
<tbody>
<tr>
<td>Jan 2010</td>
<td>218</td>
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<tr>
<td>Jan 2011</td>
<td>242</td>
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<td>Jan 2012</td>
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<td>Jan 2013</td>
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<td>Jan 2014</td>
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<tr>
<td>Jan 2015</td>
<td>369</td>
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<tr>
<td>Jan 2016</td>
<td>400</td>
</tr>
<tr>
<td>Jan 2017</td>
<td>455</td>
</tr>
<tr>
<td>Jan 2018</td>
<td>570</td>
</tr>
<tr>
<td>Jan 2019</td>
<td>649</td>
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<tr>
<td>July 2019</td>
<td>696</td>
</tr>
</tbody>
</table>
Membership

**Age Distribution**
- 100 records in the 40-45 range
- 155 records in the 45-55 range
- 129 records in the 55-65 range
- 110 records over 65

**Gender Distribution**
- 287 male, 410 female

**Most Represented Countries**
- United Kingdom: 51 records
- Germany: 39 records
- Italy: 38 records
- Spain: 32 records
- Netherlands: 31 records
- Switzerland: 28 records
- Egypt: 19 records
- Sweden: 19 records
- Belgium: 19 records
- France: 19 records
- Slovakia: 16 records
- Poland: 16 records
- Turkey: 14 records
- Greece: 13 records
- United States: 12 records
- Croatia: 12 records
- Canada: 9 records
- India: 7 records
- Austria: 7 records

**Stage in Career**
- 471 practicing
- 83 in training
- 20 retired
- 5 students

**ESC Membership Region**
- 73% Europe
- 15% Americas
- 12% Asia
- 2% Rest of World

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ESC Working Group
Adult Congenital Heart Disease
Membership
All ESC Working Groups Overview – July 2019

- W.G. on Cardiac Cellular Electrophysiology
- W.G. on Atherosclerosis and Vascular Biology
- W.G. on Thrombosis
- W.G. on Adult Congenital Heart Disease
- W.G. on CV Pharmacotherapy
- W.G. on Myocardial & Pericardial Diseases
- W.G. on Cellular Biology of the Heart
- W.G. on e-Cardiology
- W.G. on Coronary Pathophysiology and Microcirculation
- W.G. on Myocardial Function
- W.G. on Aorta & Peripheral Vascular Diseases
- W.G. on Pulmonary Circulation & Right Ventricular Function
- W.G. on Development, Anatomy and Pathology
- W.G. on CV Surgery
- W.G. on CV Regenerative & Reparative Medicine
Congresses & meetings

MEETINGS AT ESC CONGRESS PARIS

WG on ACHD General Assembly
Sunday 1 September 10:30-11:00 CEST
Paris Expo Porte de Versailles, Meeting Room 2, Zone A, Level 0
OPEN TO ALL WG MEMBERS

WG on ACHD Networking Reception
Monday 2 September 19:00-22:00 CEST
Comet Ternes "LA FABRIQUE"
OPEN TO REGISTERED WG MEMBERS ONLY
Congresses & meetings

www.euroguch2020.com

FOCUS ON

Adult congenital heart diseases in
• Exercise
• Pregnancy
• Arrhythmias
• Endocarditis
• Pulmonary hypertension
• Novel interventional and surgical therapies
• Issues beyond heart disease including precision medicine strategies
Study group on the delivery of ACHD care focused on Central/South/East-Europe

Chairs: Prof. Iveta Šimková, MD, PhD - Slovakia; Margarita Brida, MD, PhD - Croatia
Coordinator linking with the Nucleus of the ESC WG ACHD: Prof. Gerhard Diller, MD, PhD - Germany

Members:
- Prof. Tamara Kovačević Preradović, MD - Bosna and Hercegovina
- Ass. Prof. Pencho Kratunkov, MD, PhD - Bulgaria
- Rairi Ermel, MD, PhD - Estonia
- Hajnalka Olga Balint, MD - Hungary
- Petra Antonová, MD - Czech Republic
- Agnese Strenge, MD - Latvia
- Prof. Lina Gumbiene, MD, PhD - Lithuania
- Prof. Monika Komar, MD, PhD - Poland
- Roxana Enache, MD; Prof. Ioan Mircea Coman, MD, PhD - Romania
- Ljiljana Jovovic, MD, PhD; Prof. Vladislav Vukomanovic, MD - Serbia;
- Assist. Prof. Katja Prokšelj, MD, PhD - Slovenia
- Ihor H. Lebid, MD, PhD - Ukraina

Aims:
- Better understand ACHD situation, needs, issues and also opportunities in each country and the region of the Central/South/East-Europe
- Uncover inequities in access to medical and interventional treatment for ACHD patient in Central/South/East-Europe
- Improve access to high quality ACHD care to all patients throughout Europe and countries affiliated with the European Society of Cardiology
Research & publications

WG papers published:

• **ESC Working Group Position Paper: Transcatheter adult congenital heart disease interventions: organization of care** – recommendations from a Joint Working Group of the European Society of Cardiology (ESC), European Association of Pediatric and Congenital Cardiology (AEPC), and the European Association of Percutaneous Cardiac Intervention (EAPCI)

• **Genetic counselling and testing in adults with congenital heart disease: a consensus document of the ESC Working Group of Grown-Up Congenital Heart Disease, the ESC Working Group on Aorta and Peripheral Vascular Disease and the European Society of Human Genetics**
  European Journal of Preventive Cardiology, 0(00) 1–13; doi: 10.1177/2047487319854552

WG papers in writing:

• **Future and advance care planning in grown up congenital heart disease patients: recommendations from the ESC Working Group of Grown Up Congenital Heart Disease, Council on Cardiovascular Nursing and Allied Professions (CCNAP), European Association for Palliative Care (EAPC) and International Society for Adult Congenital Heart Disease (ISACHD)**
  Expected publication: early 2020
**2020 Elections**

Elections for the following positions will be open in 2020
- Vice-Chairperson
- Nucleus member

**Nucleus Member elections – timeline**

<table>
<thead>
<tr>
<th>Event</th>
<th>Timeline</th>
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<tbody>
<tr>
<td>Call for candidates</td>
<td>April 2020</td>
</tr>
<tr>
<td>Voting</td>
<td>May – June 2020</td>
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<tr>
<td>Announcement of results</td>
<td>July 2020</td>
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</tbody>
</table>

_Nucleus members are elected by the members of that same Working Group whose country of work is an ESC Member Country. Further information on eligibility criteria & election process will be available in the call for candidates._