



2020 Annual Report

International Society of Nurses in Genetics

President's Report

Dennis Cheek, ISONG President 2019-2020



To my ISONG Colleagues,

Thank you for the privilege of serving as the President of ISONG during 2020, the "Year of the Nurse and Midwife". 2020 was quite a journey for each and every one of us, as we navigated through the unprecedented global COVID-19 pandemic. Despite the many challenges we all faced, both professionally and personally, ISONG remained strong and true to our mission and vision, something of which we should all be proud.

Due to the travel restrictions, ISONG transitioned to a virtual platform for board meetings, webinars, and the 2020 Annual World Congress. Although the move to a virtual Congress was challenging, our registration and attendance numbers increased! All in all, the Congress was a successful time of learning, networking and growing together as an association.

My original Presidential goals for 2020 changed significantly as the COVID-19 pandemic emerged. I want to thank the ISONG committees, board of directors, and other volunteers for the work and progress that led to the following accomplishments:

1. **Creation of new ISONG Strategic Goals 2020-2022:**
 - a. **Increase educational offerings**
 - b. **Increase membership**
 - c. **Increase visibility of ISONG and nurses**
 - d. **Create formal partnerships**
2. **Successful virtual 2020 ISONG World Congress**, with more registrants and attendees ever in ISONG history.
3. **Provision of two research grants to ISONG members**, despite the reduction in university budgets and the limitations presented by COVID.
4. **Establishment of the *Nursing Portfolio Credentialing Commission (NPCC)***, a commission that is independent from ISONG.

As the outgoing President, I would like to take this opportunity to thank the ISONG members for their time, energy, and continued hard work. Thanks to all their efforts, ISONG is in a very strong position. Despite a slight drop in membership numbers, ISONG remains fiscally sound. The work of ISONG continues with the new strategic plan, approval of additional position statements, and the securing of additional support for another World Congress. I know that this has been an unprecedented year for all of us and sincerely hope that you continue taking some time for yourself and families.

Most Sincerely,

Dennis Cheek

Dennis Cheek
ISONG President 2019-2020



About ISONG

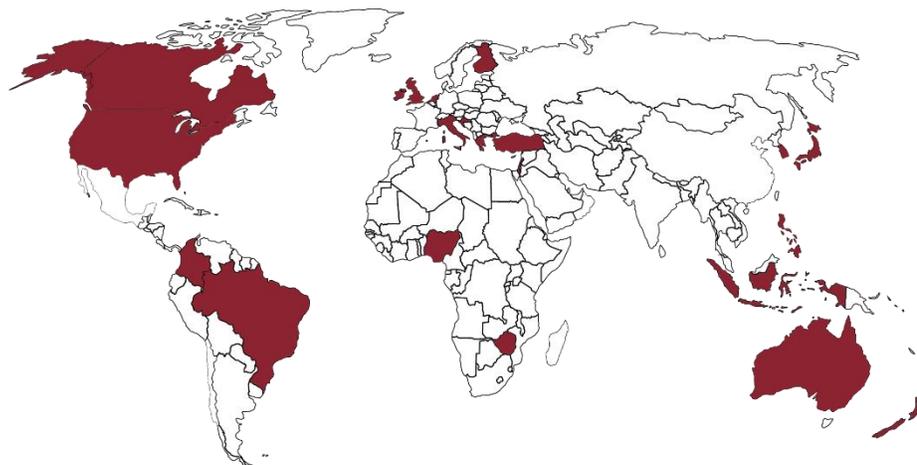
Who Is ISONG?

ISONG is an inclusive professional group serving the genetics nursing profession and the public. Internationally, nurses are engaged in genetic and genomic healthcare at all levels of policy, education, research, and clinical practice. We welcome new perspectives and look forward to the opportunity to have new members join us in shaping the future!

Our **356 members** live and work in **21 countries** across the globe:

21!

<i>Australia</i>	<i>Colombia</i>	<i>Israel</i>	<i>Nigeria</i>
<i>Brazil</i>	<i>Croatia</i>	<i>Italy</i>	<i>Philippines</i>
<i>Canada</i>	<i>Finland</i>	<i>Japan</i>	<i>Turkey</i>
	<i>Greece</i>	<i>Korea, Republic of</i>	<i>United Kingdom</i>
	<i>Indonesia</i>	<i>Netherlands</i>	<i>United States</i>
	<i>Ireland</i>	<i>New Zealand</i>	<i>Zimbabwe</i>



Mission

To serve both the nursing profession and the public. ISONG fosters and advocates for the scientific and professional development of its members and the nursing community, in the discovery, interpretation, application, and management of genomic information, for the promotion of the public's health and wellbeing. ISONG advocates for public understanding of genomic health and use of genomic information.

Vision

Caring for people's genetic and genomic health throughout the lifespan and across the continuum of health and disease.

Committee Reports



Bylaws Committee

Catherine Read, Committee Chair

A comprehensive review and revision of the Bylaws was completed. Input was solicited from the Board, ISONG Headquarters, committee chairs, and the membership. Revised Bylaws were approved by the ISONG membership on November 6, 2020.



Communications Committee

Stacy Hines-Dowell and Carolyn Allen, Committee Co-Chairs

Success was realized in most of the Communication Committee's goals! Way to go, Stacy and Carolyn.

- ✓ Maintained continuity across ISONG website and social media pages.
- ✓ Increased member engagement and expanded ISONG presence on social media.
- ✓ Realized **19%** increase of Facebook followers for a total of over **1000** followers!
- ✓ Engaged **3** Student Correspondents who covered communications during Congress. Thank you to Anndra Dumo (Finland), Stephanie Chidester (Missouri/NINR), and Abdul Kargbo (Ohio State).
- ✓ In a partnership with ACMG, the Committee collaborated with the genetics nurse practitioners to use the tag **#geneticsnursepractitioner** and **#iamageneticsNP** during the 2021 ACMG Conference.



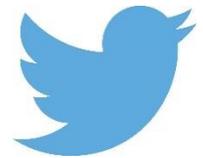
Total Page Likes: **1,087**
Total Page Followers: **1,129**



Followers: **136**



Followers: **41**



Followers: **450**

Committee Reports



Congress Planning Committee

Michael Groves and Lynnette Howington, Committee Co-Chairs

The 2020 ISONG Congress was a particularly challenging conference to plan, as we had to move to a virtual format due to the COVID-19 pandemic. The biggest hurdle was meeting the needs of a global audience that spanned 19 time zones. The flexibility and perseverance of the Congress Planning Committee, the Headquarters staff and the Congress speakers cannot be understated. The willingness of the group to try new things, exercise patience and sustain their good humor resulted in an outstanding Congress.

Due to the reduced costs associated with a virtual meeting, we were able to reduce the registration fee. We exceeded our conservative goal of 112 attendees and realized an attendance over 145, despite moving to an online virtual platform!

We relied heavily on our numerous sub-committees and want to thank them. They were essential to our success!

- **Abstracts** – Reviewed and scored 56 abstracts, mapped the schedule for the Congress sessions.
- **Moderators** – Selected and trained session moderators, who are essential for keeping the sessions running on schedule. Although our virtual format required fewer moderators, a few were still needed for the live sessions. We are thankful to the ISONG members who volunteered for this important role.
- **Hospitality** – Engaged with social media presence and the Student Correspondents.
- **Continuing Education Units** – Gathered data required for CEU submissions, submitted the applications, and prepared and sent certificates (with bountiful assistance from Headquarters office).
- **Global Panel** – Decided the format of the session, invited panelists, decided upon the content of the session, and moderated the session at Congress.
- **Pre-Congress** – Decided upon the focus of the sessions, drafted the call for proposals and reviewed and approved the content for the Pre-Congress.
- **Sponsorship and Grants** – Sourced and contacted potential sponsors and educational grant providers. Applications for grants and negotiations with sponsors were then managed by the committee and the Headquarters office.



Committee Reports



Development Committee

Theresa Wadas, Committee Chair

Our committee performs outreach activities with community organizations, educational institutions, associations, and businesses to support our mission. This includes building relationships to foster new sponsorships with genetic/genomic professional and public education.

This past year saw some tribulations due to the pandemic, but all in all we were successful in most of our endeavors:

- ✓ *DNA Day Competition* was implemented and 7 ISONG members participated. Winner was announced by Dennis Cheek at the 2020 ISONG Congress.
- ✓ Three nursing research grants sponsored by University of Connecticut, University of Pittsburgh, and Duquesne University.
- ✓ We received 1 medical educational grant from Amicus.
- ✓ Local vendors remained interested in participating at our virtual Congress.



Education Committee

Caitlin Dreisbach and Ruth Lucas, Committee Co-Chairs

The Education Committee is responsible for the facilitating and supporting the genetic/genomic continuing education and advancements for all professional nurses. Despite the pandemic, we met most of our goals.

- ✓ Met monthly, engaging in robust discussion from a diverse group of academic educators, nurse researchers, and clinicians.
- ✓ Met with the Veteran's Association (VA) to identify their needs regarding genetic/genomic education.
- ✓ Updated the links on the ISONG Education website to ensure accuracy of materials.
- ✓ Collaborated with Sarah Dewell and Membership Committee to work on the New Member Toolkit.
- ✓ Collaborated with the Association for Oncology Nurses and Patient Navigators (AONN) to develop and refine materials for their genomics education materials. Thank you to ISONG member Frank de la Rama, who presented a pre-conference session at their annual conference on genetics/genomics in oncology nursing.
- ✓ Created a membership-wide survey to find out what resources our members use for their genetic/genomic knowledge. We are using this information in our educational repository.

Committee Reports

✓ Organized a specialized steering committee for (C-NEG) led by Deborah Himes. This Steering Committee is poised to create a new Scopes and Standards for Nurse Educator credentialing. They have been in close contact with NPCC leaders, Julie and Stacey, through our committee's liaison role with Nurse Portfolio Credentialing Commission.

✓ Offered a special session for nurse educators to discuss adaptations in learning styles.



Ethics & Public Policy Committee (EPP)

Laurie Connors and *Leslie Darmofal*, Committee Co-Chairs

The Ethics & Public Policy Committee is dedicated to the evaluation of scientific and political changes as they relate to genomics and public health. The committee serves to identify needed dialogue on perspectives to serve nursing professionals and the public.

The Committee is proud to have updated the Employee Wellness Position Statement that led to it being approved by the ISONG Board of Directors. The following position papers are currently under review by ISONG lead developers:

- *Access to Genomic Healthcare: The Role of the Nurse*
- *Genetic Counseling for Vulnerable Populations: The Role of Nursing*



Global Membership Committee

Sarah Dewell and *Bobbi Laing*, Committee Co-Chairs

Our committee has worked on several initiatives this year to promote member recruitment, retainment, and engagement.

Oncology Special Interest Group (OSIG): Over the past year, the OSIG has grown and now includes 34 members with three co-leaders, Maura McCall, Theresa Swift-Scanlan, and Monica Wagner. The OSIG is fostering a partnership with a subcommittee of the ISONG Research committee to better identify interests/work of members to hopefully boost membership/participation. In addition, the OSIG started a Slack site with channels dedicated to general information, funding opportunities, papers that to share with the group, clinical topics, and research topics.

Year of the Nurse and Midwife: Although it has certainly not been the Year of the Nurse and Midwife that we imagined, it has been especially gratifying during this challenging year to highlight the efforts and accomplishments of ISONG members through this initiative. The monthly features have given ISONG members insight into the outstanding work being done in the ISONG community and helped connect us during the pandemic. This initiative included monthly features in the ISONG e-Update and ISONG social media.

Committee Reports

Regional Ambassadors: The Committee had been reorganizing the role of Regional Ambassador. We envision that regional ambassadors will connect nurses to ISONG and address country /region specific needs. Regional Ambassadors are trailblazers within their country/region to address the need for visible role models. Once capacity increases, the regional ambassadors may become a “regional ambassador team” to address education, clinical practice, and student issues. We have recently launched a Regional Ambassador Pilot initiative in Brazil and Japan. The two pilot teams are working together to share and compare strategies.

Genomics Education Kit: A genomics education kit was developed and was added to the Welcome Kit for new members. Additionally, the toolkit information was provided to the Education Committee to assist with the development of their genetics/genomics educational and clinical resources initiative.

ISONG Website Updates/Social Media: We streamlined and updated the Global Membership section of the website by reviewing the material that was on the website, eliminating duplication, suggesting a new format to organize content, and providing new content through the Year of the Nurse and Midwife initiative. We have also provided updates on the accomplishments and efforts of members to the Communications Committee for promotion on social media.

Connections with country-specific genetics nursing societies: We are working to strengthen ties between ISONG and the Brazilian and Japanese Genetic Nursing Societies by sharing information about events and tackling language barriers. We hope the two Regional Ambassador pilots in these two countries will serve to further enhance connections with ISONG.



Nominations & Awards Committee

Catherine Read, Committee Chair

Nominations: Followed procedure to elect President-Elect, Treasurer, Member-At-Large, and Student Representative.

Board members elected for 2020-2021:

- **President-Elect:** *Susan Wesmiller*
- **Treasurer:** *Lisa Aiello*
- **Member-at-Large:** *Hudson Santos*
- **Student Member:** *Dhaneesha Bahadur*

Awards: Followed procedure to select recipients of Research, Education and Practice awards. No nominee could be solicited for the Practice Award. Committee selected recipients of Research and Education awards by majority vote:

- **Research Award:** *Jennifer Sanner Beauchamp*
- **Education Award:** *Gigi Lim*

Beginning in 2021, there will be separate Nominations and Awards Committees. Refer to revised 2020 Bylaws for details.

Committee Reports



Professional Practice Committee (PPC)

Tina Mladenka and Andrea Hartgraves, Committee Co-Chairs

We are proud of our committee's work to support efforts, develop and evaluate scope and standards of practice, credentialing, and ongoing genetics nursing practice issues.

- ✓ Provide HQ with talking points for responding to emails and phone calls yearly.
- ✓ Completed survey for coding/billing/ reimbursement. Results examined and presented to ISONG members.
- ✓ Expanded patient educational resources.
- ✓ Expanded clinical representation at ISONG Congress. 6 clinical abstracts were submitted (exceeded our goal of 3!).



Research Committee

Michelle Wright and Tara Albrecht, Committee Co-Chairs

We reviewed ISONG research grant applications and awarded 2 research grants. We set up a subcommittee to complete tasks outlined by the board after strategic planning initiatives were decided. The subcommittee is coordinating with the social committee and congress committee to obtain mini-presentations from a variety of presenters to highlight research being done by members of our organization. We've also reached out to the oncology SIG and ONSEN to work on strengthening connections and access to genomic resources.

356 Members

21 Countries

1 Organization



Thank You for Supporting the 2020 ISONG Congress



Thank You for the Medical Education Grant received from



Board Reports



Secretary Report

Ansley Stanfill

The ISONG Secretary works with headquarters to draft meeting minutes, develop bullet points for the newsletter, serves as the board liaison for the Research Committee.

- ✓ Completed the SOAR strategic plan.
- ✓ Worked with the Education Committee to develop a repository of genomics resources, and developed a subcommittee to highlight the research accomplishments of our members through podcasts.
- ✓ Collaborated with the NINR symptom science center.



Treasurer Report

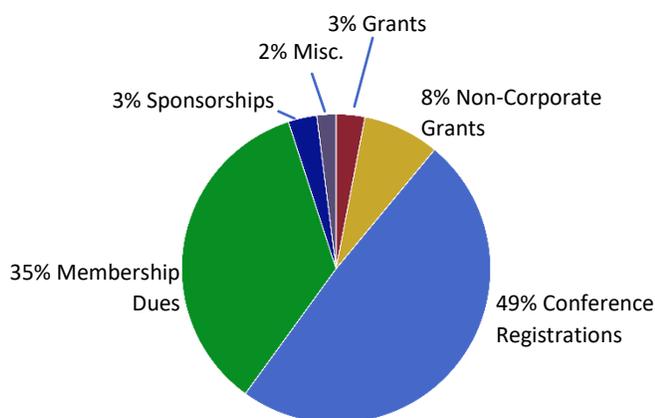
Lisa Aiello

The ISONG Treasurer works closely with Kassalen Meetings & Events, LLC, ISONG's association management company. The Treasurer reviews the monthly financial statements and provides a report to the ISONG Board of Directors each month.

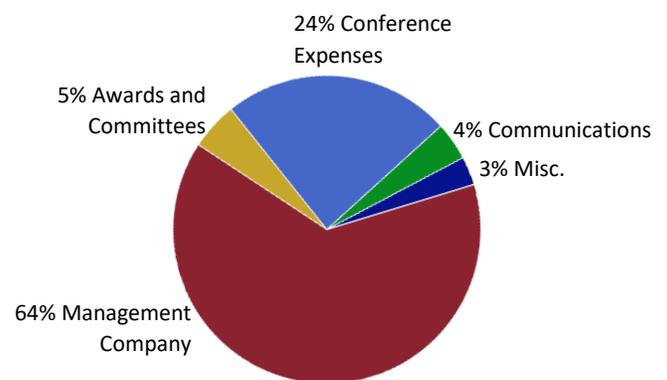
ISONG is proud to report a net profit of \$17,203 for the 2020 fiscal year, despite the many challenges resulting from the COVID-19 pandemic. ISONG finances are strong going into 2021.

ISONG 2020 Balance Sheet	
January 1, 2020	\$ 114,621
December 31, 2020	\$ 131,824
Net Profit 2020	\$ 17,203

Income 2020



Expenses 2020





Student Ambassador Report

Dhaneesha Bahadur

Being the Student Representative on ISONG's Board of Directors allows for contributions of great significance to ISONG's success. During the COVID-19 pandemic we as a group were faced with difficult decisions, and yet ISONG persevered. We persevered because we recognized the importance of relationships, regardless of how these relationships are maintained. My platform in the role of Student Representative has been to **foster mentorship by creating and sustaining connections between members**. Keeping connections alive were challenging, but the nurses of ISONG not only met the challenge, but thrived.

Throughout my time as Student Representative, I had multiple opportunities to work with peers and create an environment conducive to learning and sharing. Because of ISONG's transparency and open communication, remaining connected during a pandemic was achieved. I made myself available to ISONG's community by corresponding with potential student members and communicated with our current student population by providing emails. During the pandemic, virtual sessions were created where people from all aspects of ISONG joined and discussed how the pandemic affected their lives, personally and professionally. In September of 2020 Dr. McKenzie Wallace and I worked together to present **"How to Make a Poster"** for ISONG members to prepare for their poster presentations. By utilizing a virtual platform, we provided expert knowledge to mentor our members professionally. In October of 2020 I had the opportunity to represent ISONG at the NSNA (National Student Nurse's Association) virtual conference. By explaining the resources I received as a mentee of ISONG, I became the mentor for the nursing student population.

The transparency in ISONG is refreshing and allows for ISONG members to contribute to our success. The role of student representative advocates for all members to be treated fairly and provides the diversity ISONG needs to thrive. I look forward in my continued membership and welcome future mentoring opportunities.

Save The Date
2021 ISONG World Congress
November 5 – 7, 2021

Look for more details soon in your inbox and isong.org.



Executive Director Report

Beth Kassalen, Kassalen Meetings and Events

ISONG Focuses on Relevancy, Engagement, and Sustainability

When the coronavirus pandemic swept full force across the world in March 2020, our immediate focus was how to **keep ISONG relevant, community-focused, and financially stable**. I am proud to say that the Board of Directors, Committee chairs and members contributed to helping ISONG weather the virus storm on all three focal points.

In March 2020, the ISONG Board and its Committees were just putting the final touches on the strategic plan that would serve as a road map for activities through 2022. Ironically, comments and projects calling for more online access to genetic education and virtual delivery methods foreshadowed what was to come. Let me say **“mission accomplished and check”** to our strategic goals of offering more virtual meetings and engaging a wider genetics nursing audience in 2020!

Knowing that **global networking and compelling educational content** are always expectations of the ISONG Annual Congress, the ISONG Congress Planning Committee worked diligently with Amy Spikula at Headquarters to ensure that ISONG could deliver those two needs using a virtual platform.

We found success through the Airmeet® virtual platform, which offered a networking lounge, small group tables, exhibit booths, and the speed networking feature. Designing **3** days of genetic content, managing **30** posters, **7** keynotes, **56** abstract speakers, sponsors and exhibitors, all virtually, was no small feat. Anyone who participated knows that the Congress was not your typical “Zoom” call; the platform delivered!

COVID-19 placed a heavy financial burden on ISONG members, some of whom experienced the closing of their labs, a quick transition to virtual teaching, reduction in pay or employer benefits, lack of funding, and even early retirement. The ISONG Board analyzed options to lighten that burden and was able to deliver a virtual Congress for approximately **half of the typical registration fee**. ISONG ended the 2020 fiscal year without realizing a financial loss, and in fact, saw a small net profit! Refer to Lisa Aiello’s Treasurer Report for specific details.

Membership was down approximately 10% in 2020, which was to be expected as members focused on their jobs, families, and health. ISONG is an incredibly strong community. We want to help our members navigate their struggles, not complicate them. We hope that 2021 allows more members to join or renew their memberships without hardship.

I am going to end my report by reiterating ISONG’s four strategic goals that will guide us through 2021:

- *Expand Educational Offerings*
- *Increase Membership*
- *Increase the visibility of ISONG and Nurses*
- *Create Formal Partnerships*

All committees have created their projects and initiatives and are working diligently to achieve them. **If you feel the call to service**, one or more of the ISONG committees will gladly welcome you. Read about the committee and activities in this Annual Report, you will undoubtedly be inspired to get involved!

2019-2020 ISONG Board of Directors

Thank you to the **2019-2020 ISONG Board of Directors** for sharing their passion, intellect, insight, experience and resources with ISONG!



President
Dennis Cheek, RN, PhD, FAHA



President-Elect
Rebecca Kronk, PhD, MSN, CRNP, FAAN, CNE



Past-President
Cathy Read, PhD, RN



Treasurer
Lisa Aiello, PhD, RN, AOCNS



Secretary
Ansley Stanfill, PhD, RN



Member-at-Large
Masakazu Nishigaki, PhD, RN, CGC



Student Representative
Dhaneesha Bahadur, MSN, RN, LNCC



Member-at-Large
Linda D. Ward, PhD, FNP-C



Executive Director
Beth Kassalen, MBA