

CASCADE

NEWSLETTER NOVEMBER 2022

Dear all,

We hope that our annual newsletter finds you in good health. We are pleased to send you our fifth annual CASCADE newsletter!

We also take the opportunity to thank you for your ongoing support. We welcome participants who have newly enrolled in the study and thank those who have already completed the first follow-up survey. The second follow-up survey will be released early 2023.

The third annual lottery will take place in January 2023. One lucky participant will win a gift card of CHF 300. The winning canton will be announced on our website (swisscascade.ch) and our next newsletter. In 2022 the lucky participant was from Geneva.

Your CASCADE study team
swisscascade-nursing@unibas.ch

We thank the following clinical sites for their support:



STATE OF THE PROJECT AND NEXT STEPS



The iCascade study is taking place in Israel since January 2022.



Our partners in **Korea** have already recruited **411 individuals** and conducted **21 interviews** about **HBOC** for the **K-CASCADE** study. We will compare our results to find out how to better manage cancer risk.

In Switzerland, we continue our recruitment in the cantons of **Basel-Stadt, Berne, Geneva, Jura, Ticino, Fribourg, Vaud and Zürich**.

Until now there are a total of **603 individuals** from **431 Familien**. **327 families** are concerned with hereditary breast and ovarian cancer (**HBOC**) and **104 families** are concerned with **Lynch Syndrome**.



Our findings show that:

- Genetic information is difficult to understand, even for individuals who had genetic testing.
- Sharing information with relatives about the genetic syndrome is a complex process and depends on characteristics of the person and their family.
- Most participants would like to maintain the responsibility of sharing genetic information with relatives, possibly with the assistance of digital technology.

**It is very important that you complete the surveys and provide the study with long-term information about your health.
Thank you in advance for your help.**

NEW TEAM MEMBERS



Mrs. Rachel Bunger obtained her degree in Glasgow and worked for the UK government for nearly two decades. Mrs. Bunger will be assisting the CASCADE team with recruitment.

OUR INTERNATIONAL PARTNERS

Dr. Sun-Young Park spent a year with the CASCADE team in Switzerland as a research fellow. She received funding from the Korean Health Industry Development Institute.



Dr. Sue Kim is a professor of Nursing at the Yonsei University and the Principal Investigator of the K-CASCADE study in Korea.



Dr. Sivia Bar-Noy is a professor of Nursing at the Tel Aviv University in Israel and co-investigator of the iCascade study.



Dr. Efrat Dagan is a professor of Nursing at the University of Haifa in Israel and co-investigator of the iCascade study.



INTERNSHIP WITH THE CASCADE CONSORTIUM

Ms. Neha Rizvi and **Mrs. Anum Siddiqui**, who study for their Master's degree in Genetic Counseling at Northwestern University, Chicago, IL, USA completed a 6-week research internship in Switzerland and became familiar with the CASCADE study and the Swiss healthcare system.



Papers published

Pedrazzani, C.; Aceti, M.; Schweighoffer, R.; Kaiser-Grolimund, A.; Bürki, N.; Chappuis, P.O.; Graffeo, R.; Monnerat, C.; Pagani, O.; Rabaglio, M.; et al. The Communication Chain of Genetic Risk: Analyses of Narrative Data Exploring Proband–Provider and Proband– Family Communication in Hereditary Breast and Ovarian Cancer. *J. Pers. Med.* 2022, 12, 1249. <https://doi.org/10.3390/jpm12081249>

Sarki, M.; Ming, C.; Aissaoui, S.; Bürki, N.; Caiata-Zufferey, M.; Erlanger, T.E.; Graffeo-Galbiati, R.; Heinemann, K.; Heintzelman-Schwarz, V.; Monnerat, C.; et al. Intention to Inform Relatives, Rates of Cascade Testing, and Preference for Patient-Mediated Communication in Families Concerned with Hereditary Breast and Ovarian Cancer and Lynch Syndrome: The Swiss CASCADE Cohort. *Cancers* 2022, 14, 1636. <https://doi.org/10.3390/cancers14071636>

Pedrazzani, C. Ming, C.; Bürki, N.; Caiata-Zufferey, M.; Chappuis, P.O.; Duquette, D.; Heinemann, K.; Heintzelmann-Scharz, V.; Graffeo-Galbiati, R.; Merajver, S.D.; et al. Genetic Literacy and Communication of Genetic Information in Families Concerned with Hereditary Breast and Ovarian Cancer: A Cross-Study Comparison in Two Countries and within a Timeframe of More Than 10 Years. *Cancers* 2021, 13, 6254. <https://doi.org/10.3390/cancers13246254>

Conference presentations

 <p>GBCC 2022 Global Breast Cancer Conference 2022</p>	<p>Conceptions of responsibility to communicate genetic information and risk about hereditary breast and ovarian cancer: a Swiss-Korean qualitative comparative analysis, [Poster], GBCC 2022. Presented by Monica Aceti</p> <p>Determinants for or against undergoing prophylactic mastectomy and oophorectomy in unaffected Women with BRCA1 or BRCA2 Mutation in Switzerland: A Mixed-Methods Study, [Poster], GBCC 2022. Presented by Reka Schweighoffer</p> <p>Predict the openness of communication of genetic risk in families with hereditary breast and ovarian cancer syndrome? [Poster], GBCC 2022. Presented by Vasiliki Baroutsou</p>
 <p>ESMO congress PARIS 2022</p>	<p>Pre-surgery demographic, clinical, and symptom characteristics associated with different self-reported cognitive processes in patients with breast cancer, [Poster], ESMO 2022. Presented by Yu-Yin Su Allemann.</p>
 <p>ELSIcon 2022: Innovating for a Just and Equitable Future</p>	<p>Privacy and utility of genetic testing among families with hereditary cancer syndromes living in three countries: The International Cascade Screening experience [Workshop Presentation], ELSIcon 2022. Presented by Maria Katapodi, Sue Kim, Sivia Bar-Noy, Maria Caiata-Zufferey and Efrat Dagan</p>
 <p>ESHG EUROPEAN HUMAN GENETICS CONFERENCE 2022</p>	<p>Making the right choice. How unaffected women carrying BRCA1 or BRCA2 germline mutations decide for prophylactic mastectomy to reduce cancer risk, [Podium presentation], EHGC 2022, Vienna, Austria. Presented by Maria Caiata-Zufferey</p> <p>The communication chain: a qualitative analysis of patient-provider and patient-family communication in hereditary cancers, [Poster], EHGC 2022, Vienna, Austria. Presented by Carla Pedrazzani</p> <p>Relatives from hereditary breast and ovarian cancer and lynch syndrome families forgoing cascade testing: findings from the Swiss CASCADE cohort, [Poster], ESHG 2022, Vienna Austria. Presented by Mahesh Sarki</p>
 <p>EPH EUROPEAN PUBLIC HEALTH CONFERENCE</p>	<p>Swiss cost-effectiveness analysis of universal screening for Lynch syndrome of patients with colorectal cancer followed by cascade genetic testing of relatives, [Poster], 14th European Public Health Conference, 2021. Presented by Islam Salikhanov</p>

We thank the following organizations for their support to the CASCADE study:

