1. AN ONLINE RETROSPECTIVE ILC DATABASE.

Here, we will construct a retrospective database that contains a collection of samples, data and model systems that will be used as a repository for the ILC research community.
We will start with a web-based format that initially will be accessible for the Consortium members only, but if successful and safe, can be opened up to everyone.

The system should contain but is not limited to:
- Clinical data (ended prospective trials and ongoing trials, etc)
- Pathological data (cohorts/TMAs, etc)
- Genomics data
- Availability of paired samples (primary/mets/liquids)
- Model systems (cell lines/organotypic tumour cultures/PDX/transgenic models)
- Guide lines/suggestions for diagnosis and ILC models.

The ICR has an up and running cBioportal-like repository, that could serve for hosting samples that are done and dusted, so we could have an ILC-specific set containing genomics, PA and follow-up data.

Action points:

I. I have registered the domain WWW.ELBCC.ORG, which will be central platform for our consortium initiative. At first I will just put a mission statement on there and links to the current members, but the idea is to host information on our meetings, patient advocacy info, have a designated (secure) member's page where the above data are posted, etc, etc. I will do the initial hosting and maintenance, and involve the IT people from the UMCU to help with meta data analysis and secure login and storage.
(PATRICK, volunteer?)
If this works out well, this needs to be expanded and the databases managed, for which we need a designated person. I will initiate a COST application (see below, funding) together with a number of members to probe options for finances to employ an individual who can do this.
(PATRICK, CHRISTINE, DARRAN, ANNE, CHRIS) also see funding.

II. I would like to collate the logo's from the participating institutes for the website. Please send me a vector-based format and a link to your lab's website.
(ALL)

III. Retrospective data mining in luminal/ER+ trials to extract ILC data (ALL). This would be a good start for a retrospective repository to post on the website.

2. PROSPECTIVE TRIAL AND OPTIONS FOR FOLLOW-UP STUDIES

The general perception was that we need to initiate ILC-specific prospective trials and sampling. The current ILC-specific efforts include:

ROIo @ICR, (NCT03620643),
Crizotinib in advanced E-cad negative, ER positive lobular breast cancer or Diffuse gastric cancer

NoName MSKCC, (NCT00581750)
Molecular Genetic Basis of Invasive Breast Cancer Risk Associated With Lobular Carcinoma in Situ

NoName Mayo Clinic, (NCT00620087)
Molecular Breast Imaging in Women With Atypia and LCIS

GLACIER (CRUK): (NCT00536718)
A Study to Investigate the Genetics of LobulAr Carcinoma In Situ in EuRope

PELOPS Dana Fraber Cancer Institute (NCT02764541)
Palbociclib and Endocrine Therapy for LObular Breast Cancer Preoperative Study

GELATO NKI/AvL (NCT03147040)
AssessinG Efficacy of Carboplatin and ATezOlizumab in Metastatic Lobular Breast Cancer

NoName (NCT02206984)
Endocrine Response in Women With Invasive Lobular Breast Cancer

NoName (NCT03030404)
Hereditary Gastric Cancer Syndromes: An Integrated Genomic and Clinicopathologic Study of the Predisposition to Gastric Cancer

In short, just a few trials and only 1 that specifically targets ILC biochemistry!!, so plenty to be done

Action points:

I. It all starts with uniform (pathological) criteria to diagnose and include ILC. Now, this definition process resides in the realm of Pathologists and the resulting advice to WHO etc. Notwithstanding this expertise, I think we should construct a broader platform that is based on Pathology but implements input from cancer biologists and geneticists. Ideally this would also yield solid inclusion criteria and functional biomarkers to commence lobular-specific intervention trials.
   I think it would be an idea to have a designated session on this. Perhaps an interactive session during the 2nd international ILC symposium in Pittsburgh later this year? I have contacted Steffi for this and probe her interest. Independently, this could/should also be done within a Pathology panel set-up and lead to a specific advisory platform.
   (MATTHIAS, pathologists and anyone with a clear opinion on how to differentially diagnose ILC.)
   (PATRICK: contacted Oesterreich/Metzger for an interdisciplinary session during the coming Pittsburgh meeting)

II. (Also based on (I)) Define options for trial set-up. I propose to have a session during the next meeting in Sept/Okt where interested members from our consortium can pitch a new intervention option for LCIS/ILC.
   When the date is set, I will send a reminder on getting input and ideas for this.
   (ALL)

III. Define consensus on sampling, clinical and biochemical response parameters, and prospective analyses (omics).
   This is hard to define in a clear action point, because it depends on (I) and the specific intervention concept of the trial, which could be defined in (II). Preferable would be a multi-center basket-type trial (inclusion of the ER-, Her2+, p53 mutant, PIK3CA wt versus mutant, etc).
   Pros and Cons for either a neo-adjuvant window trial or a metastatic setup were discussed. Also some good ideas from Chris Lord about defining an intermediate (Ki67 or other) response point, defining responders and follow arms/treatments.
   Most options will also largely depend on the intervention type and rationale, so I think we need a separate designated session for this, which can be done during the next meeting

IV. Christine Desmedt opted for a setup whereby the emphasis is collection rather than intervention. Such a 'trial' would be ideal for large numbers and the collection of material for biochemical and genetic follow up, and provide a steady flow of fresh material for PDX/PDO generation. Any ongoing trial could be eligible for this (ROlo?, GELATO?) Depending on consent and setup. Also ICGC might be a source for this.
   I think it would be opportune if a clinician in our consortium would coordinate such an effort together with Christine, and get input on preferences for collection in the context of analyses and model building.
   (CHRISTINE, SABINE, ELINOR, VIVIANNE, ANDREW, AGNES, ELSKEN)

3. FUNDING OPTIONS

With multiple national and international options and specific needs for specific types of research, we have distilled two clear options that will be followed up. Others are attached as pdf (slides from the meeting).

I. *The European Cooperation in Science and Technology (COST).*

This is a funding organisation for the creation of research networks, supporting a maximum of 130K€/year.
Exclusively dedicated to cover collaboration activities, such as workshops, conferences, working group meetings, training schools, short-term scientific missions, and dissemination and communication activities.
7+ COST members, at least half must be 'inclusiveness target countries'

Gender bias should be taken into account.

As initiator I will apply for our consortium for the obvious reasons. Jos Jonkers had applied for this previously and has provided a template.

The following core exists:

Derksen	(NL, M)	Senkus	(PO, F)
Desmedt	(BE, F)	Cserni	(HU, M)
O'Connor	(IRL, M)	Kulka	(Hu, F)
Salomon	(FR, F)	Thomas	(LX, M)

If additional people wanna join, that is of course more than fine but make sure you come up with a member that has a good track record on the subject, and make sure he/she balances your gender.

Deadline is in September. I will lead this and keep you updated. Please mail me if you want to be added.

II. *Marie Curie Innovative training Network.*

Training networks that generally support up to 15 PhD students
5-10 partners could take part in this with 1-2 PhD students per partner
Secondments to other academic partners and to industry

For now, it is best to digest this option and think about how we can produce a comprehensive applications that covers our mission statement; *i.e.* a broad approach to ILC understanding and treatment. I propose to have apply for this (1 grad student each) using the following optional expertise/division:

3x cell biology

4x omics

4x translational/clinical

2x bioinformatics

2x Industry partner (several options; nanotech, 3d hydrogel, antagonising peptides/antibodies)

This call appears to be a good option to provide some glue for the consortium and ensure interactions because of the secondments

We can discuss strategy and make a final decision on content during the next meeting (September/October)

Deadline for this call will probably be January 15, 2020.

III. *Other options are depicted in the attached slides.*

In addition, the UK Grand Challenge was opted, as were Susan Komen and the US department of defence.

Mobilising support from Patient Advocates could be a potential source as well.

(ALL)

4. OUTREACH AND PATIENT ADVOCACY (PA).

This important subject was discussed in the context of setting up a EU-wide ILC-specific PA initiative. Currently this is not present in any of the Consortium members' countries.

I have contacted Europa Donna through the Dutch Breast cancer Society to inform them of our Consortium Initiative and ask for input and support (take the lead) in organising this.

The general idea is to have an organisation comparable to the US-based Lobular Breast Cancer Alliance (LBCA) (https://lobularbreastcancer.org/).

Christos Sotiriou is already a member of the LBCA advisory board and I have recently joined the editorial board, so we are well-represented. The board will functionally rotate every 3 years.

Hopefully the EU PA's can join the LBCA (as a sister organisation?) or setup their own with close ties to the US-LBCA. Input from Europa Donna will be decisive in this.

Ideally, we could already include some PA contributions during our next meeting(s) and involve them in plenary discussion on experimental/trial setup, funding options etc.

(PATRICK, CHRISTOS, ALL)

5. FOLLOW-UP MEETINGS, SYMPOSIA, ETC

I. *Our Consortium:*

To keep the momentum going I want to immediately follow-up these minutes with proposing dates for a 3rd meeting.

In light of the Marie Curie ITN call and the summer break I propose to get together in September or October (details will follow) aiming at:

1. General progress, plans, further specifications on the retrospective database/website
2. A science session in which the ITN parties will present a pitch to illustrate their expertise and elaborate on how to use the PhD student
3. Novel options for clinical trials. Now that we have extensively talked about how to setup future trials and discuss options and limitation, I feel we should proceed to having Consortium members presenting actual ideas for trials and discussing feasibility.
4. If applicable, a patient advocacy session.

II. *External options:*

Depending on our interaction frequency, it was mentioned that we could also have satellite meetings during existing congresses and Symposia which many of us might attend.

Best options for this are perhaps:

1. The 2nd International ILC Symposium. Pittsburgh, PA. (Expected Spring 2020)
2. San Antonio BC meeting (December 2019 and/or 20)
3. EACR/AACR breast cancer meetings (suggestions?)