

CLL database

Aneela Majid
am242@le.ac.uk

Focal point for data

- Foster collaborations between groups.
- Samples are NOT being banked, the collector will still have material.
- Data analysis of rare subgroups.
- Accurately define phenotypes and genotypes.

Recommendations

- Collect and store samples in the same way.
- Collect the same type of information.
- Set guidelines (like ERIC) for standardisation of tests and data collection.

Data for collection

- DOB
- NHS number
- Age diagnosis
- Sex
- WCC diagnosis
- Stage diagnosis
- Treated/untreated (date first treatment, time to treatment from diagnosis and duration of treatment)
- Autoimmune disease
- LDH
- Other cancer/transformation to Richters
- Progressive/non-progressive
- Survival status (date of death)
- Coombs status
- VH mutational status
- P53 mutations/dysfunction
- Cytogenetic analysis

- OTHER?????

Procedure

- Set up centre numbers for unique identification.
- Each centre enters data for patients.
- Email contact for each centre to facilitate collaborations.
- Password protected data.

Central database

- Test database set up

<https://www.tissuebank.dundee.ac.uk/cll/tissueBank>

user name: tester

password:tester