



WG2: CLINICAL IMPLEMENTATION GAPS AND OPPORTUNITIES



QUESTIONS IN WG2

- 1. What are the key gaps in our knowledge about clinical implementation of genomics/pharmacogenomics in relation to SJS/TEN?**
- 2. What recent advances in clinical implementation of genomics/pharmacogenomics have the greatest likelihood of contributing to an eradication of preventable causes of SJS/TEN?**
- 3. What are key barriers to using genomics/pharmacogenomics to impact clinical outcomes and care for SJS/TEN?**
- 4. What resources or infrastructures needs would enable clinical implementation of genomics/pharmacogenomics in relation to SJS/TEN?**
- 5. Can recent developments in basic research and pharmacosurveillance be leveraged to advance clinical implementation in SJS/TEN (and vice versa)? If yes, how?**
- 6. What are the most promising opportunities for clinical implementation of genomics/pharmacogenomics to impact SJS/TEN over the next 5 years?**
- 7. What is the evidence base needed to implement screening/testing? What are alternatives to large prospective clinical trials?**

PRE MEETING SURVEY

What are the most promising opportunities for clinical implementation of genomics/pharmacogenomics to impact SJS/TEN over the next 5 years?

Genomic markers that identify particular demographic clusters in admixed populations who reside in different locations due to globalization could be a very useful tool if such groups are at increased risk to develop certain drug/SJS events.

Low cost PGx assay that can be included in state/national health program.

Genotypes in the medical record, next-generation sequencing for clinical purposes.

HLA-B*1502/HLA-A*3101 and carbamazepine, HLA-B*5801 and allopurinol

Implementing testing in high risk populations and studying impact.

Piloting of pre-emptive testing

SUMMARY OF WG2

- Iatrogenic events, so moral obligation to act on SJS
- We don't know the burden of SJS/TEN problem
 - Where is the SJS-HLA study in Asian Americans?
- What will move the needle? Genetics alone is often not enough
- What are the downstream implications of changing therapy?
 - Are the alternatives better, same, worse?
- The focus on one gene-one drug won't be favorable economically.
- Pilot study to see how people behave when faced with the data.
 - Survey patients, loved ones, general population about choices between disease control and SJS risk
- Who bears the extra cost and how does it get mitigated?
- Qualitative methods from patients.

Do HLA now rather than when you are organ donor?