

MyeloProliferative Neoplasms (MPNs) Registry in Iran

Ghaemshar

Mazandaran university of medical science

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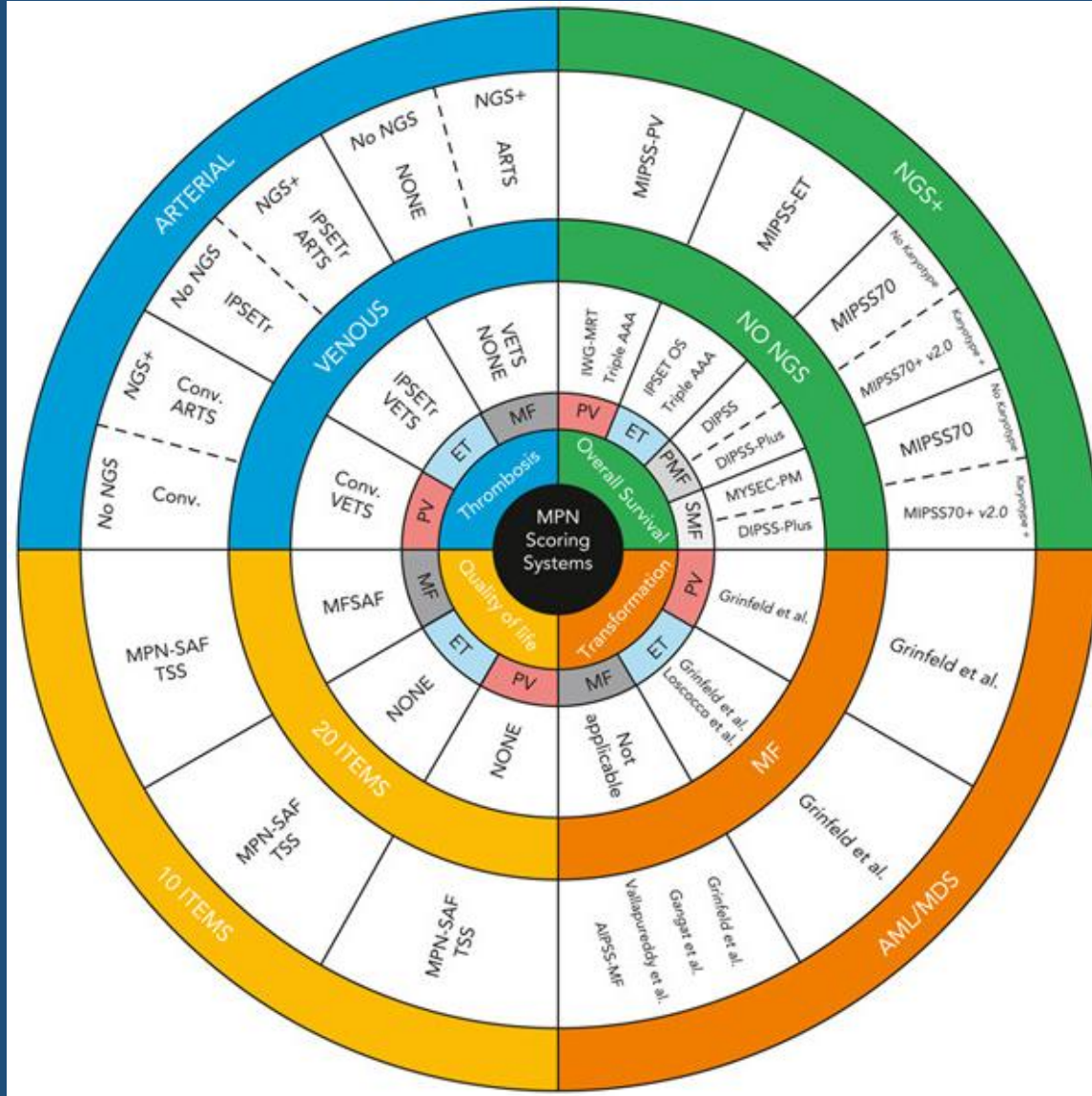
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- We are regularly looking at the published literature and updates >>> make sure that these guidelines are very nimble, and they are adjusted to reflect current practice
- in September 2023, *momelotinib (Ojjaara)*, the fourth JAK inhibitor, became available for the treatment of intermediate or high-risk MF, including primary MF or secondary MF in adults with anemia
- *Top 5 Most Popular MPN Articles of 2024*
- *Personalizing MPNs Management, Monitoring*
- *NGS (12 genetic markers are sufficient)*
- *Myeloproliferative Neoplasm (MPN) Scoring Systems for Clinical Practice*

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- *This registry will establish a clinical annotation database: help to better understand this diseases, optimal therapy and improve their outcomes lead to the preparation of appropriate guidelines for treatment and transplantation according to our own region.*
- *This project will provide new insights on the molecular profiling of patients with MPN*
- *It will be used as future resource for observational studies related to MPN*
- *Assisting in the preparation of multi-center information at the country level*
- *Assisting in the preparation of multicenter information at the global level*

- *IR.MAZUMS.REC.1402.18416*
- *13/1/2023*
- *Members of the strategic committee*
- *Location*
- *By reviewing articles, clinical guidelines, WHO and CDC and case report forms, primary items were extracted*
- *Cohort up to 10 years*
- *Data collection:*
- *Data includes: a range of clinical measures, disease-associated factors, details of treatment and its results, complications during treatment, molecular and cytogenetic data, and survival outcome (up to 10 years)>>>> Mini Data Base (MDS)*
- *Annually updated*

Outcome Measures:

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- *Survival [Time Frame: Annually or at the time of transformation of disease, up to 10 years]*
- *General patient characteristics*
- *Physical symptoms, Splenomegaly, hepatomegaly*
- *Disease risk score*
- *Strain echo*
- *Quality of life: MPN-SAF TSS questionnaire*
- *MPN treatment type received*
- *Transfusion dependence status*
- *Current Blood Work*
- *Identifying MPN mutations*
- *BMT details and complications*
- *Portal hypertension*
- *Pulmonary hypertension*
- *Thrombosis*
- *Disease progression*

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Results in first year: (Ghaemshahr)

- 1400 = 400000

- Of the 49 eligible patients with MPNs: MF >>> 3 >>> 1
candidate for transplant

PV >>> 26 >>> 2 MI

ET >>> 20 >>> 1 blue toe

1 TIA

1 DVT

1 death

- The median age: 59 years (range, 47-73 years)

- They are follow every 3 months

- Referred for strain echo