

## DALLAS SGLS 2019

Karyopharm Roundtable –

- Manufacturers of Selinexor (XPVIO)
- Great cookbook “Eating Well Through Cancer” by Holly Clegg
  - Recipes by side effect

**“We are care-partners, not caregivers...we are partnering in this journey together”**

**Dr. Durie – Updates from International Myeloma Working Group and Black Swan Initiative**

- MGUS could start as early as when patients are 20-30 years old
- If we can prevent MGUS, then will prevent progression to smoldering and in the end prevent progression to MM
- 60% of patients live in the Asia/Pacific Region
- Current studies on MRD Negative – patients can still relapse or is there a cutoff? MRD negative for 1,3,5 years? For now, looks to be 5 years MRD negative, there will be no MM in future
- Developing studies attempting to understand immune system status of patients effecting MRD
- Bench marking how earlier intervention improves MRD
- Need to study MGUS to see who will progress and who will not so we can know who to treat

## High Risk Smoldering MM

- CESAR Trial – KRD + transplant
  - Results 60-70% MRD negative
- Ascent Trial – DKRD
  - Results even better

## Regarding treating MM earlier

- Paper in publication “Blood ”- showing Dormant MM cells in blood – window for new treatment to keep MGUS from progressing

## MM Causes

- Agent Orange
- 9/11 survivors
- Roundup?

## CAR t-cells

- Why only 1 year response – patients are in end stage of disease
- If given to healthier patients will there be a longer response and outcomes
- What if we modify CAR t-cell therapy for repeated dosing
- What about a CAR t-cell combo

## Nurse Leadership Board

- Measles –
  - Infected 4 days from exposure
  - Can pass on for 14 days - when having symptoms
- Chronic Pain –
  - Myeloma Canada YouTube – video on CBD oil for pain  
[www.youtube.com/watch?v=JsL--trSNb4](http://www.youtube.com/watch?v=JsL--trSNb4)
- Have your vitamin B levels checked if you have neuropathy

**“Get to know your nurse!”**

## Amgen (presenter Diane Mozack)

### New Treatments in Pipeline...

- BiTE – Bispecific T-cell Engager
  - AMG 420 – Phase 1 trial
    - For relapsed and/or refractory MM
    - 4 weeks on/2 weeks off
  - Half Life BiTE – for extended use – weekly
    - Currently in trial
- MCL-1 Inhibitors
  - AMG 176
  - AMG 397 (oral)
- AMG 420 Amgen – AMG420
  - Continuous IV pump after a few days in hospital to watch for side effects
- AMG710

## **Jansen (presenter Mieesha, Kim Bernie)**

- Dara – any large changes in weight, up or down, tell physician
- Dara is an IGG Kappa antibody, therefore your IGG levels are affected if you are on Dara
- Janssen Care Path [www.janssencarepath.com](http://www.janssencarepath.com)
  - - Helps you find the resources you may need to get started and stay on track.
- Janssen believes in “Shared Decision-Making Strategies”

**“Patients should be participating in their health care decisions”**

**“Patient centered care”**

- Suggested Reading – “Trust Your Doctor, But Not That Much”

**“Your Oncologist is not God”**

## **Karyopharm (Presenter Dr. Shah)**

Recently approved by the FDA...

- Selinexor (XPOVIO) 20 mg tablet for use with DEX – 2X wk (M/W)
  - SINE XPO1 (Selective Inhibitor of Nuclear Export)
  - XPOVIO (selinexor) is approved in the U.S. in combination with dexamethasone for the treatment of adult patients with relapsed or refractory multiple myeloma (RRMM) who have received at least four prior therapies and whose disease is refractory to at least two proteasome inhibitors

(Velcade, Kyprolis, Ninlaro), at least two immunomodulatory agents (Thalidomide, Revlimid, Pomalyst), and an anti-CD38 monoclonal antibody (Dara, Empliciti)

- 25% overall response – survival rate up to 15 months
- This a “bridge” drug and not a front line treatment
- This is the result of the STORM trial
- BOSTON trial (Velcade, Selinexor, DEX) – in Phase 3
- STOMP trial (Selinexor Combo Therapy - added to any other combination of therapies) – in Phase 2
- Side effects can be managed by dose reduction or by stopping and starting Selinexor
- **KARYFORWARD** – Support Center [www.karyforward.com](http://www.karyforward.com)
  - A patient support and resource center for Karyopharm medications.

## Working Groups

- New Groups
  - **CaringBridge -Dedicated to Your Health Journey**  
**[www.caringbridge.org](http://www.caringbridge.org)**
    - Your personal CaringBridge website is your place to share health updates, photos and videos with the people who care about you.
  - Private, Protected and Ad-Free
    - “You’re in control of your privacy. Customize your settings to make your updates private or public. Your personal data is never sold, and there’s no outside advertising.”
  - Coordinate Help

- Your personal CaringBridge website is designed to rally your family and friends together, to offer you support when and how you need it.
- **LotsaHelpingHands.com** <https://lotsahelpinghands.com>
  - Easily organize help for someone in need

## **Dr. Durie**

- Standard of care triplets
  - KRD (Kyprolis, Revlimid, DEX)
  - KCD (Kyprolis, Cytoxan, DEX)
  - DARA + RD (Dara, Revlimid, DEX) – Non- Transplant Setting
- Quadruplets being used
  - Dara + VRD (Velcade, Revlimid, DEX)
  - Dara + VTD (Velcade, Thalidomide, DEX)
  - Dara + KRD (Kyprolis, Revlimid, DeX)
- Venetoclax Update
  - Trial has been reopened because positive responses in 11:14 translocation patients...”The FDA has lifted a partial clinical hold placed on the phase III CANOVA trial, which is investigating the combination of Venetoclax (Venclexta) and dexamethasone in comparison with pomalidomide (Pomalyst) and dexamethasone in patients with relapsed or refractory multiple myeloma and a transformation (11;14) abnormality”
- MISC
  - No problem with collecting stem cells after Dara
  - Ask Doctor if lower dosage of drug you are on is still effective
  - Empliciti, Pomalyst, DEX in relapse setting

- Dr. Durie is not a fan of targeted therapies...leaves other components of MM untreated, with exception of Venetoclax. This drug is beneficial.
- MassSpec vs MRD testing
  - Much more sensitive
- New IMiDS are currently being developed

### **Celgene (presenter Chad Saward)**

- Celgene/Bristol Meyers Squib merger (BMS)
- Both Celgene and BMS reinvest cost of drugs back into research

#### MM Therapies

- CAR T-cell BB2121
- CAR T-cell BB2121-7
- JCARH 125 (Juno)
  - High risk MM, 7 lines of previous therapy, 80% response

#### NEW Therapies

- CC220
- CC9284
- **Coming soon**
  - **MMCenterForNurses.Com**
- Patient support ([www.celgenepatientsupport.com](http://www.celgenepatientsupport.com))
  - “If you have commercial insurance, you may qualify for the Celgene Commercial Co-pay Program. If you qualify, your out-of-pocket co-pay responsibility will be \$25 or less (subject to annual benefit limit) for your prescribed Celgene medicine”

- “This program provides up to:
  - \$10,000 per calendar year to help meet co-pay/co-insurance costs
  - Eligibility criteria include:
    - Commercial or private insurance that does not cover the full cost of the prescribed Celgene medicine
    - Residence in the United States or US territory
    - Patients with government healthcare insurance (for example, Medicare [Parts B, C, and D], Medicaid, Medigap, TriCare, CHAMPVA) are not eligible
    - Other eligibility requirements and restrictions apply.” ([celgenepatientsupport.com](http://celgenepatientsupport.com))
- Celgene Patient Assistance Program
  - If you do not have health insurance or enough coverage to pay for your medicine, the **Celgene Patient Assistance Program (PAP)\*** may be able to provide you with the prescribed Celgene medicine at no cost. To qualify, you must meet certain financial criteria.” ([celgenepatientsupport.com](http://celgenepatientsupport.com))

## Takeda

- My Mentor Connections
  - My Mentor Connections is there to support and encourage you in your journey with multiple myeloma. Mentors are patients and caregivers who devote their time to answer questions and provide support to you



as a patient, caregiver, friend, or family member over the phone. [www.mymentorconnections.com](http://www.mymentorconnections.com)

- Takeda Oncology 1Point – financial support
  - Works with your healthcare provider and your insurance company to help get you started on your medication
  - Identifies available financial assistance that may be right for you
  - Connects you to additional support services and resources.  
[www.takedaoncology1point.com/patient/home](http://www.takedaoncology1point.com/patient/home)
- “PatientsLikeMe” on-line blog to join. Find answers, support and a path forward with people like you.  
[www.patientslikeme.com](http://www.patientslikeme.com)
- New Drugs
  - Tak-079 – CD38 monoclonal anti-body, Phase 1
  - Tak-573 – CD 38 monoclonal anti-body (partnership with Tera), Phase 1
  - Tak-169 – CD38 monoclonal anti-body, for patients not responding to Dara (not in trial yet)

### **Peripheral Neuropathy and You (Presenter Debbie Burns)**

- Peripheral Neuropathy is damage to the nerves at the body’s “periphery” (arms, hands, fingers, feet, legs), **BUT** can also involve sites controlled by the Autonomic Nervous System, (over which we have no control), and the Central Nervous System
- Peripheral Neuropathy can affect each of the Peripheral Nerve Pathways

- Sensory Nerves – “Carry messages from the receptors all around the body to the brain”
- Motor Nerves – “Carry messages from the brain to the muscles that control movement”
- Autonomic nerves – “carry messages from spinal cord to organs to stimulate blood pressure and body temperature control, breathing, digestion, heart rate, dilation and contraction of pupils, urination, and sexual arousal”
- Symptoms of Sensory Peripheral Neuropathy - Numbness, tingling, prickling, lack of temperature sensation, burning, freezing, jabbing or throbbing sensation, sensation of wearing stockings or gloves, feeling like there is sand in your shoes, loss of knowing where your feet are on the ground, loss of balance when eyes closed, loss of reflexes, tinnitus (ringing in the ear)
- Symptoms of Motor Peripheral Neuropathy – weakness, muscle cramping, loss of muscle mass, difficulty writing, difficulty feeling or manipulating small objects, lack of coordination or falling
- Symptoms of Autonomic Neuropathy – intolerance of heat, difficulty adjusting to the dark, dizziness caused by change in blood pressure when sitting or standing up, digestive problems, feeling full after eating very little, urinary/bladder issues, erectile dysfunction
- Peripheral Neuropathy can be caused by both MM and treatments for MM (Velcade, Ninlaro, Thalidomide, Revlimid, Pomalyst)
- Ask your doctor if you can lower your medication dosage once your disease is reduced and managed

- Peripheral Neuropathy is bi-lateral (same on both sides). If your pain is one sided, could be spine related

**THANK YOU, DEBBIE BURNS FOR ALL THIS VALUABLE INFORMATION. A NEW “PERIPHERAL NEUROPATHY AND YOU” BOOKLET IS AVAILABLE TO DOWNLOAD. [www.myeloma.org/sites/default/files/resource/upn\\_en\\_2019\\_a1\\_web.pdf](http://www.myeloma.org/sites/default/files/resource/upn_en_2019_a1_web.pdf)**

**PAPER COPY TO BE AVAILABLE SOON!!**

### **SUGGESTIONS FROM DALLAS ON PERIPHERAL NEUROPATHY**

- Shoes
  - Hoka Shoes
  - Cole Hahn, Johnson Murphy (visit Ebay clothing store/shoes for reduce prices)
  - Kenkoh Sandals – Happy Feet Massage Sandals
  - All shoes should have an orthotic, cushioned footbed
  - Wear orthotic slippers
  - Wear orthotic beach shoes
  - Wear compression socks
  - CBD for Life – foot cream
  - Thor Laser (Cold Laser Therapy)
  - For leg cramps - Pickle juice -calms the nerves (you don't even need to swallow, just swish)
    - You can purchase as a sport drink online

## **KNOCK OUT MYELOMA VIDEO**

[www.youtube.com/watch?v=Km7EcfIMZX4](http://www.youtube.com/watch?v=Km7EcfIMZX4)

Check out this great video!!!