

#MMSM transcript

Healthcare Social Media Transcript

From: Sun Jun 29 18:00:00 PDT 2014
To: Sun Jun 29 19:10:00 PDT 2014
change time period

What is **#MMSM**? Who were the influencers during this time period? **#MMSM analytics**

[Healthcare Conference](#) - [Healthcare Tweet Chats](#) - [Healthcare Analytics](#)

mtmdphd

#mmsm - Let's start. Please introduce yourselves...

Sun Jun 29 18:00:24 PDT 2014

myelomateacher

RT **@mtmdphd**: **#mmsm** - Let's start. Please introduce yourselves...

Sun Jun 29 18:00:57 PDT 2014

mtmdphd

Next **#mmsm** TweetChat 6/29 8-9pm CT w/ **@brendanweiss** Topic: amyloidosis T1 What is amyloidosis? T2 Treatment/management T3 Future directions

Sun Jun 29 18:01:14 PDT 2014

mtmdphd

I am a heme/onc and helped start the **#mmsm** Tweetchat with **@myelomateacher**

Sun Jun 29 18:01:54 PDT 2014

mtmdphd

Dr. Weiss - **@brendanweiss** is discussing amyloidosis tonight... **#mmsm**

Sun Jun 29 18:02:16 PDT 2014

brendanweiss

I am a hematologist specializing in **#amyloidosis** and **#myeloma** **@PennMedicine** <http://t.co/DUWI6ypH4I> **#mmsm**

Sun Jun 29 18:02:43 PDT 2014

mtomasson

RT **@mtmdphd**: Next **#mmsm** TweetChat 6/29 8-9pm CT w/ **@brendanweiss** Topic: amyloidosis T1 What is amyloidosis? T2 Treatment/management T3 Fut...

Sun Jun 29 18:02:48 PDT 2014

myelomateacher

I'm Cindy - DX w/ myeloma in 7/2008. Currently in VGPR- Velcade maintenance **#MMSM**

Sun Jun 29 18:03:02 PDT 2014

- mtmdphd** It's a beautiful summer day in WI. Not sure how many are on tonight. But give a shout out if you are... #mmsm
Sun Jun 29 18:03:05 PDT 2014
- kat4gators** @mtmdphd Kathy AL patient dx 2/13, HDC/SCT 4/13, CR #mmsm
Sun Jun 29 18:03:08 PDT 2014
- myelomateacher** RT @mtmdphd: Dr. Weiss - @brendanweiss is discussing amyloidosis tonight... #mmsm
Sun Jun 29 18:03:28 PDT 2014
- mtmdphd** @kat4gators Welcome #mmsm
Sun Jun 29 18:03:33 PDT 2014
- brendanweiss** @MTomasson good to see you on the chat - what goes on with #amyloidosis at WashU? #mmsm
Sun Jun 29 18:03:55 PDT 2014
- myelomateacher** Who else is out there? #MMSM
Sun Jun 29 18:04:01 PDT 2014
- danaholmes911** Dana, Dx w/ SMM in 1/2012 #mmsm
Sun Jun 29 18:04:17 PDT 2014
- mtmdphd** I think Dr. Weiss has a lot of content, so keep your intro/shout outs as we start into T1 - What is amyloidosis? #mmsm
Sun Jun 29 18:04:43 PDT 2014
- brendanweiss** #Amyloidosis results from the deposit of misfolded proteins in many organs: heart, kidney, nerves liver others... #mmsm
Sun Jun 29 18:05:27 PDT 2014
- mtmdphd** RT @brendanweiss #Amyloidosis results from the deposit of misfolded proteins in many organs: heart, kidney, nerves liver others... #mmsm
Sun Jun 29 18:05:49 PDT 2014
- brendanweiss** #Amyloidosis can be confined to one organ (localized) or in multiple organs (systemic) #mmsm
Sun Jun 29 18:06:02 PDT 2014
- mtmdphd** @BrendanWeiss - How is the diagnosis usually made? #mmsm
Sun Jun 29 18:06:18 PDT 2014
- myelomateacher** @brendanweiss What are signs of #amyloisdosis #MMSM
Sun Jun 29 18:06:30 PDT 2014

danaholmes911

RT @mtmdphd @BrendanWeiss - How is the diagnosis usually made? #mmsm

Sun Jun 29 18:06:38 PDT 2014

danaholmes911

RT @brendanweiss #Amyloidosis can be confined to one organ (localized) or in multiple organs (systemic) #mmsm

Sun Jun 29 18:06:52 PDT 2014

brendanweiss

@mtmdphd @BrendanWeiss By astute clinicians suspecting the diagnosis and amyloid deposits by Congo Red stain on tissue biopsy #mmsm

Sun Jun 29 18:07:23 PDT 2014

danaholmes911

RT @brendanweiss By astute clinicians suspecting the diagnosis and amyloid deposits by Congo Red stain on tissue biopsy #mmsm

Sun Jun 29 18:07:57 PDT 2014

mtmdphd

@BrendanWeiss What are signs? What tips people off? Who should be tested? #mmsm

Sun Jun 29 18:08:13 PDT 2014

danaholmes911

Should we routinely test for #amyloidosis in likely MGUS or SMM patients ? #mmsm

Sun Jun 29 18:08:43 PDT 2014

danaholmes911

RT @mtmdphd @BrendanWeiss What are signs? What tips people off? Who should be tested? #mmsm

Sun Jun 29 18:08:56 PDT 2014

brendanweiss

@mtmdphd @BrendanWeiss Heart failure, protein in the urine, peripheral or autonomic neuropathy, unexplained weight loss, bruising #mmsm

Sun Jun 29 18:09:06 PDT 2014

myelomateacher

RT @mtmdphd: @BrendanWeiss What are signs? What tips people off? Who should be tested? #mmsm

Sun Jun 29 18:09:32 PDT 2014

brendanweiss

Excellent review on the approach to amyloidosis by Comenzo <http://t.co/Ce8sGfWQ8Y> #mmsm

Sun Jun 29 18:09:52 PDT 2014

mtmdphd

@brendanweiss - are all multiple myeloma patients tested? Should they be? What is incidence of amyloidosis? #mmsm

Sun Jun 29 18:10:08 PDT 2014

mtmdphd

@brendanweiss Thanks #mmsm

Sun Jun 29 18:10:18 PDT 2014

danaholmes911

At what mg or g level does proteinuria or albuminuria in 24 hour become significant or suspicious for further testing? #mmsm

Sun Jun 29 18:10:50 PDT 2014

- brendanweiss** [@DanaHolmes911](#) Not clear, but there should be a high index of suspicion, especially lambda light only and signs/symptoms [#mmsm](#)
Sun Jun 29 18:10:52 PDT 2014
- myelomateacher** What' autonomic neuropathy? [#MMSM](#)
Sun Jun 29 18:11:02 PDT 2014
- danaholmes911** RT [@brendanweiss](#) [@DanaHolmes911](#) Not clear, but there should be a high index of suspicion, especially lambda light only and signs/symptoms [#mmsm](#)
Sun Jun 29 18:11:23 PDT 2014
- brendanweiss** [@DanaHolmes911](#) about 500 mg/24 hours, but there is a wide range [#mmsm](#)
Sun Jun 29 18:11:27 PDT 2014
- kat4gators** [@brendanweiss](#) [@mtmdphd](#) Unexplained edema, enlarged liver? Those were my key symptoms. [#mmsm](#)
Sun Jun 29 18:11:35 PDT 2014
- mtmdphd** MT [@DanaHolmes911](#) At what level does proteinuria or albuminuria in 24hr become significant or suspicious for further testing? [#mmsm](#)
Sun Jun 29 18:11:47 PDT 2014
- danaholmes911** RT [@brendanweiss](#) [@DanaHolmes911](#) about 500 mg/24 hours, but there is a wide range [#mmsm](#)
Sun Jun 29 18:11:59 PDT 2014
- amyloid_planet** [@DanaHolmes911](#) we should routinely ask pts w "MGUS" or "SMM" if they have PN or sxs of CHF and make sure no proteinuria. [#mmsm](#)
Sun Jun 29 18:12:05 PDT 2014
- mtmdphd** [@kat4gators](#) [@brendanweiss](#) Also enlarged tongue or easy bruising/bleeding [#mmsm](#)
Sun Jun 29 18:12:09 PDT 2014
- mtmdphd** [@Amyloid_Planet](#) Thank you for joining Dr. Zonder [#mmsm](#)
Sun Jun 29 18:12:29 PDT 2014
- danaholmes911** RT [@Amyloid_Planet](#) [@DanaHolmes911](#) we shud routinely ask pts w "MGUS" or "SMM" if they have PN or sxs of CHF and make sure no proteinuria. [#mmsm](#)
Sun Jun 29 18:12:46 PDT 2014
- brendanweiss** [@MyelomaTeacher](#) sx/sx of autonomic neuropathy: low blood pressure, slow emptying on stomach contents, constipation [#mmsm](#)
Sun Jun 29 18:12:47 PDT 2014
- myelomateacher** Are certain people more susceptible to [#amyloidosis](#) th en others- risk factors? [#MMSM](#)
Sun Jun 29 18:12:48 PDT 2014

- brendanweiss** @Amyloid_Planet great that you could join! #mmsm
Sun Jun 29 18:13:04 PDT 2014
- brendanweiss** @mtmdphd @kat4gators Yes absolutely #mmsm
Sun Jun 29 18:13:25 PDT 2014
- danaholmes911** Once we have an MGUS or SMM BMB sample, why not test routinely at this stage, even if asymptomatic? #mmsm
Sun Jun 29 18:13:39 PDT 2014
- mtmdphd** T1 What is amyloidosis? #mmsm
Sun Jun 29 18:13:47 PDT 2014
- brendanweiss** @mtmdphd Animated video to help understand amyloidosis - highly recommended <http://t.co/5sMV1JjCf6> #mmsm
Sun Jun 29 18:14:05 PDT 2014
- danaholmes911** RT @brendanweiss @mtmdphd Animated video to help understand amyloidosis - highly recommended <http://t.co/7DbItjVRaZ> #mmsm
Sun Jun 29 18:14:16 PDT 2014
- kat4gators** What are your thoughts on AL being separate disease from MM or pre-cursor? #mmsm
Sun Jun 29 18:14:29 PDT 2014
- brendanweiss** Amyloidosis awareness book for patients and their caregivers <http://t.co/byWEB4oPiF> #mmsm
Sun Jun 29 18:14:35 PDT 2014
- tweetchat** RT @mtmdphd: To "join" the #mmsm Twitter discussion you can just search #mmsm & follow feed on Twitter or HootSuite or use <http://t.co/sCnB...>
Sun Jun 29 18:14:35 PDT 2014
- mtmdphd** @DanaHolmes911 I think congo red testing for amyloid common. Not sure if universal. Good point. @BrendanWeiss - comments? #mmsm
Sun Jun 29 18:14:39 PDT 2014
- danaholmes911** RT @mtmdphd @DanaHolmes911 I think congo red testing for amyloid common. Not sure if universal. Good point. @BrendanWeiss - comments? #mmsm
Sun Jun 29 18:14:54 PDT 2014
- mtmdphd** RT @brendanweiss Amyloidosis awareness book for patients and their caregivers <http://t.co/u3ZQcp4XMN> #mmsm
Sun Jun 29 18:14:56 PDT 2014
- danaholmes911** RT @mtmdphd RT @brendanweiss Amyloidosis awareness book for patients and their caregivers <http://t.co/1dvkky17h> #mmsm
Sun Jun 29 18:15:04 PDT 2014

- mtmdphd** RT @kat4gators What are your thoughts on AL being separate disease from MM or pre-cursor? #mmsm
Sun Jun 29 18:15:06 PDT 2014
- myelomateacher** Can a person have #Amyloidosis without #myeloma? #MMSM
Sun Jun 29 18:15:10 PDT 2014
- mtmdphd** @MyelomaTeacher Yes #mmsm
Sun Jun 29 18:15:21 PDT 2014
- brendanweiss** @kat4gators AL without CRAB features or high bone plasma cells ($\geq 10\%$) has a better prognosis #mmsm
Sun Jun 29 18:15:28 PDT 2014
- amyloid_planet** RT @brendanweiss: @mtmdphd Animated video to help understand amyloidosis - highly recommended <http://t.co/5sMV1JjCf6> #mmsm
Sun Jun 29 18:15:38 PDT 2014
- danaholmes911** RT @brendanweiss @kat4gators AL without CRAB features or high bone plasma cells ($\geq 10\%$) has a better prognosis #mmsm
Sun Jun 29 18:15:46 PDT 2014
- mtmdphd** @kat4gators MM can produce amyloidosis. Amyloidosis often associated with but not necessarily a pre-cursor #mmsm
Sun Jun 29 18:15:56 PDT 2014
- brendanweiss** @MyelomaTeacher Yes, only about 10% of patients with amyloidosis have CRAB features of #myeloma #mmsm
Sun Jun 29 18:16:07 PDT 2014
- kat4gators** @MyelomaTeacher That's me!! :) #mmsm
Sun Jun 29 18:16:24 PDT 2014
- mtmdphd** RT @brendanweiss @MyelomaTeacher Yes, only about 10% of patients with amyloidosis have CRAB features of #myeloma #mmsm
Sun Jun 29 18:16:45 PDT 2014
- mtmdphd** Any other Q's on T1? #mmsm
Sun Jun 29 18:16:57 PDT 2014
- brendanweiss** Important to consider the other common forms of amyloidosis: ATTR and AA <http://t.co/owZHno5Qvc> #mmsm
Sun Jun 29 18:17:24 PDT 2014
- danaholmes911** RT @DanaHolmes911 Once we have an MGUS or SMM BMB sample, why not test routinely at this stage, even if asymptomatic? #mmsm
Sun Jun 29 18:17:30 PDT 2014

- myelomateacher** If you develop #AL is that considered a relapse in #myeloma? #MMSM
Sun Jun 29 18:17:52 PDT 2014
- brendanweiss** @DanaHolmes911 @DanaHolmes911BMBx is least sensitive site for detection of amyloid deposits #mmsm
Sun Jun 29 18:17:55 PDT 2014
- mtmdphd** RT @brendanweiss Important to consider the other common forms of amyloidosis: ATTR and AA <http://t.co/IV2mkXdLia> #mmsm
Sun Jun 29 18:18:01 PDT 2014
- danaholmes911** RT @brendanweiss @DanaHolmes911 @DanaHolmes911BMBx is least sensitive site for detection of amyloid deposits #mmsm
Sun Jun 29 18:18:14 PDT 2014
- mtmdphd** @MyelomaTeacher No. Not necessarily... #mmsm
Sun Jun 29 18:18:28 PDT 2014
- brendanweiss** @MyelomaTeacher in #myeloma @amyloidosis can occur after multiple relapses #mmsm
Sun Jun 29 18:18:35 PDT 2014
- kat4gators** My core BMB was 10%, aspirate 7%. No other MM indications. Not sure exactly what I have. #mmsm
Sun Jun 29 18:18:57 PDT 2014
- mtmdphd** @brendanweiss I was taught to biopsy of the area of involvement -- heart, gut, nerve, etc... #mmsm
Sun Jun 29 18:19:05 PDT 2014
- danaholmes911** Can localized amyloid develop in soft tissue in treated AL w/ FLC WNL ? #mmsm
Sun Jun 29 18:19:10 PDT 2014
- danaholmes911** RT @mtmdphd @brendanweiss I was taught to biopsy of the area of involvement -- heart, gut, nerve, etc... #mmsm
Sun Jun 29 18:19:17 PDT 2014
- mtmdphd** @kat4gators Likely primary amyloid #mmsm
Sun Jun 29 18:19:22 PDT 2014
- brendanweiss** @mtmdphd Yes, that is the highest yield #mmsm
Sun Jun 29 18:19:32 PDT 2014
- brendanweiss** @mtmdphd @kat4gators Would agree #mmsm
Sun Jun 29 18:19:49 PDT 2014

- danaholmes911** RT [@brendanweiss](#) [@mtmdphd](#) Yes, that is the highest yield [#mmsm](#)
Sun Jun 29 18:20:00 PDT 2014
- mtmdphd** Can keep some T1 Q's going as flow into T2 - Amyloidosis Treatment/management [#mmsm](#)
Sun Jun 29 18:20:01 PDT 2014
- brendanweiss** Therapy should be individualized based on amyloid type and organ involvement [#mmsm](#)
Sun Jun 29 18:20:24 PDT 2014
- myelomateacher** What ways do you treat [#AI](#) [#MMSM](#)
Sun Jun 29 18:20:24 PDT 2014
- brendanweiss** Treatment paradigm is to eliminate precursor protein and/or its deposition into organs [#mmsm](#)
Sun Jun 29 18:20:42 PDT 2014
- mtmdphd** T2 RT [@brendanweiss](#) Therapy should be individualized based on amyloid type and organ involvement [#mmsm](#)
Sun Jun 29 18:21:00 PDT 2014
- brendanweiss** Multidisciplinary teams with experience in the rare condition are critical for diagnosis and management [#mmsm](#)
Sun Jun 29 18:21:04 PDT 2014
- kat4gators** [@mtmdphd](#) [@brendanweiss](#) hoping my clone is especially indolent. ;) [#mmsm](#)
Sun Jun 29 18:21:05 PDT 2014
- mtmdphd** RT [@brendanweiss](#) Treatment paradigm is to eliminate precursor protein and/or its deposition into organs [#mmsm](#)
Sun Jun 29 18:21:10 PDT 2014
- danaholmes911** Does Cardiac MRI stand alone to Dx Cardiac [#amyloidosis](#) 100% or is biopsy premier diagnostic for heart? [#mmsm](#)
Sun Jun 29 18:21:12 PDT 2014
- mtmdphd** T2 - Is there a "best" amyloidosis therapy? [#mmsm](#)
Sun Jun 29 18:21:26 PDT 2014
- danaholmes911** RT [@brendanweiss](#) Multidisciplinary teams with experience in the rare condition are critical for diagnosis and management [#mmsm](#)
Sun Jun 29 18:21:26 PDT 2014
- danaholmes911** RT [@brendanweiss](#) Treatment paradigm is to eliminate precursor protein and/or its deposition into organs [#mmsm](#)
Sun Jun 29 18:21:33 PDT 2014

- danaholmes911** RT @brendanweiss Therapy should be individualized based on amyloid type and organ involvement #mmsm
Sun Jun 29 18:21:43 PDT 2014
- brendanweiss** @DanaHolmes911 Cardiac MRI is not a gold standard biopsy is #mmsm
Sun Jun 29 18:21:43 PDT 2014
- mtmdphd** @DanaHolmes911 Just had this case. Biopsy gold standard. Cardiac MRI better than Echo #mmsm
Sun Jun 29 18:21:56 PDT 2014
- danaholmes911** RT @mtmdphd @DanaHolmes911 Just had this case. Biopsy gold standard. Cardiac MRI better than Echo #mmsm
Sun Jun 29 18:22:10 PDT 2014
- danaholmes911** RT @brendanweiss @DanaHolmes911 Cardiac MRI is not a gold standard biopsy is #mmsm
Sun Jun 29 18:22:18 PDT 2014
- brendanweiss** @mtmdphd No - there is no 1 best therapy for #amyloidosis - individualized therapy is necessary #mmsm
Sun Jun 29 18:22:26 PDT 2014
- mtmdphd** @brendanweiss @DanaHolmes911 thanks. Brendan actually gave me feedback on a case I saw recently. Seen "negative" echo +MRI few times #mmsm
Sun Jun 29 18:22:32 PDT 2014
- mtmdphd** RT @brendanweiss @mtmdphd No - there is no 1 best therapy for #amyloidosis - individualized therapy is necessary #mmsm
Sun Jun 29 18:22:38 PDT 2014
- brendanweiss** Outstanding recent update on the management of AL amyloidosis by Merlini et al <http://t.co/1ZWg83lkYI> #mmsm
Sun Jun 29 18:22:43 PDT 2014
- mtmdphd** T2 - Brendan - can you go over Rx recs... #mmsm
Sun Jun 29 18:22:53 PDT 2014
- myelomateacher** @brendanweiss How is that done? #mmsm
Sun Jun 29 18:22:57 PDT 2014
- danaholmes911** RT @brendanweiss Outstanding recent update on the management of AL amyloidosis by Merlini et al <http://t.co/PO5molsfzW> #mmsm
Sun Jun 29 18:23:04 PDT 2014
- amyloid_planet** RT @DanaHolmes911: RT @brendanweiss Treatment paradigm is to eliminate precursor protein and/or its deposition into organs #mmsm

Sun Jun 29 18:23:13 PDT 2014

danaholmes911

What role does BNP or Tropinin have in Dx of Cardiac [#amyloidosis](#)? [#mmsm](#)

Sun Jun 29 18:24:27 PDT 2014

brendanweiss

T2 - treatment for AL [#amyloidosis](#) frontline is either bortezomib or alkylator (melphalan) based [#mmsm](#)

Sun Jun 29 18:24:46 PDT 2014

danaholmes911

RT [@brendanweiss](#) T2 - treatment for AL [#amyloidosis](#) frontline is either bortezomib or alkylator (melphalan) based [#mmsm](#)

Sun Jun 29 18:24:56 PDT 2014

brendanweiss

T2 - some patients can proceed directly to high dose melphalan and SCT [#mmsm](#)

Sun Jun 29 18:25:03 PDT 2014

mtmdphd

RT [@brendanweiss](#) T2 - treatment for AL [#amyloidosis](#) frontline is either bortezomib or alkylator (melphalan) based [#mmsm](#)

Sun Jun 29 18:25:09 PDT 2014

myelomateacher

Could a person have protein deposits in multiple locations or is it usually just one organ? [#MMSM](#)

Sun Jun 29 18:25:17 PDT 2014

danaholmes911

Which patients ? RT [@brendanweiss](#) T2 - some patients can proceed directly to high dose melphalan and SCT [#mmsm](#)

Sun Jun 29 18:25:26 PDT 2014

brendanweiss

[@DanaHolmes911](#) These biomarkers increase sensitivity for detection of cardiac involvement [#mmsm](#)

Sun Jun 29 18:25:33 PDT 2014

amyloid_planet

[@mtmdphd](#) latest regimens have ~90% response rate. Deep, pref lengthy hematologic responses desirable. Impact risk of death, dialysis. [#mmsm](#)

Sun Jun 29 18:25:37 PDT 2014

mtmdphd

[@DanaHolmes911](#) [@brendanweiss](#) Melphalan based seems pretty underwhelming now. Most seen Vd or CyBorD approaches. Thoughts? [#mmsm](#)

Sun Jun 29 18:25:44 PDT 2014

danaholmes911

RT [@brendanweiss](#) [@DanaHolmes911](#) These biomarkers increase sensitivity for detection of cardiac involvement [#mmsm](#)

Sun Jun 29 18:25:45 PDT 2014

myelomateacher

Would a SCT be recommended? [#MMSM](#)

Sun Jun 29 18:25:59 PDT 2014

myelomateacher

RT @brendanweiss: T2 - treatment for AL #amyloidosis frontline is either bortezomib or alkylator (melphalan) based #mmsm

Sun Jun 29 18:26:11 PDT 2014

mtmdphd

MT @Amyloid_Planet @mtmdphd latest regimens ~90% resp rate. Deep, pref lengthy hemeC ORR desirable. Impact risk of death, dialysis. #mmsm

Sun Jun 29 18:26:32 PDT 2014

brendanweiss

@mtmdphd @DanaHolmes911 My typical frontline is CyBorD #mmsm

Sun Jun 29 18:26:36 PDT 2014

kat4gators

How much do specific chromosomal abnormalities go into developing treatment plans? I'm t11:14 #mmsm

Sun Jun 29 18:26:41 PDT 2014

danaholmes911

RT @brendanweiss @mtmdphd @DanaHolmes911 My typical frontline is CyBorD #mmsm

Sun Jun 29 18:26:53 PDT 2014

mtmdphd

@brendanweiss Me too except when I have found in presence of MM after the fact... #mmsm

Sun Jun 29 18:27:12 PDT 2014

brendanweiss

@MyelomaTeacher In highly selected fit patients with limited organ involvement #mmsm

Sun Jun 29 18:27:15 PDT 2014

mtmdphd

RT @brendanweiss @mtmdphd @DanaHolmes911 My typical frontline is CyBorD #mmsm

Sun Jun 29 18:27:26 PDT 2014

mtmdphd

RT @Amyloid_Planet: @mtmdphd latest regimens have ~90% response rate. Deep, pref lengthy hematologic responses desirable. Impact risk of de...

Sun Jun 29 18:27:36 PDT 2014

danaholmes911

RT @Amyloid_Planet latest regimens have ~90% response rate. Deep, pref lengthy hem responses desirable. Impact risk of death, dialysis. #mmsm

Sun Jun 29 18:27:40 PDT 2014

brendanweiss

@kat4gators not much importance in my view at this point @Amyloid_Planet thoughts? #mmsm

Sun Jun 29 18:27:56 PDT 2014

brendanweiss

Bortezomib is a very important and active drug in AL <http://t.co/4LBgOfcty8> #mmsm

Sun Jun 29 18:28:24 PDT 2014

mtmdphd

T2 1L Amyloid - CyBorD - then what? Auto SCT, Len maintenance, Vel? #mmsm

Sun Jun 29 18:28:30 PDT 2014

- danaholmes911** RT @brendanweiss Bortezomib is a very important and active drug in AL <http://t.co/jepShbPQfa> #mmsm
Sun Jun 29 18:28:39 PDT 2014
- brendanweiss** High dose melphalan and transplant is an important treatment for some patients at experienced centers <http://t.co/XQsDfomFhT> #mmsm
Sun Jun 29 18:28:40 PDT 2014
- myelomateacher** RT @brendanweiss: @mtmdphd @DanaHolmes911 My typical frontline is CyBorD #mmsm
Sun Jun 29 18:28:48 PDT 2014
- danaholmes911** RT @DanaHolmes911 RT @brendanweiss Bortezomib is a very important and active drug in AL <http://t.co/jepShbPQfa> #mmsm
Sun Jun 29 18:28:56 PDT 2014
- siewlee18** RT @mtmdphd: T2 - Brendan - can you go over Rx recs... #mmsm
Sun Jun 29 18:29:00 PDT 2014
- mtmdphd** T2 Carfilzomib seems active vs. MM but ? #CardioOnc signal may be scary in amyloid (esp known cardiac involvement) #mmsm
Sun Jun 29 18:29:08 PDT 2014
- danaholmes911** RT @MyelomaTeacher RT @brendanweiss: @mtmdphd @DanaHolmes911 My typical frontline is CyBorD #mmsm
Sun Jun 29 18:29:12 PDT 2014
- brendanweiss** @mtmdphd If unable to reach CR, then HDT or Lenalidomide based #mmsm
Sun Jun 29 18:29:17 PDT 2014
- mtmdphd** @siewlee18 Thank you for joining #mmsm
Sun Jun 29 18:29:20 PDT 2014
- danaholmes911** RT @brendanweiss @mtmdphd If unable to reach CR, then HDT or Lenalidomide based #mmsm
Sun Jun 29 18:29:29 PDT 2014
- mtmdphd** @brendanweiss So if in CR -> not Auto SCT #mmsm
Sun Jun 29 18:29:36 PDT 2014
- brendanweiss** @Amyloid_Planet any thoughts on bortezomib and cardiotoxicity in AL? #mmsm
Sun Jun 29 18:29:38 PDT 2014
- danaholmes911** RT @mtmdphd T2 Carfilzomib seems active vs. MM but ? #CardioOnc signal may be scary in amyloid (esp known cardiac involvement) #mmsm
Sun Jun 29 18:29:46 PDT 2014

brendanweiss

@mtmdphd Yes would stop chemo #mmsm

Sun Jun 29 18:29:59 PDT 2014

mtmdphd

@brendanweiss Thanks #mmsm

Sun Jun 29 18:30:14 PDT 2014

danaholmes911

RT @brendanweiss @Amyloid_Planet any thoughts on bortezomib and cardiotoxicity in AL? #mmsm

Sun Jun 29 18:30:15 PDT 2014

danaholmes911

RT @mtmdphd @brendanweiss So if in CR -> not Auto SCT #mmsm

Sun Jun 29 18:30:23 PDT 2014

brendanweiss

@DanaHolmes911 @mtmdphd We are doing this study @PennCancer <http://t.co/mDKWbNA8uz> #mmsm

Sun Jun 29 18:30:28 PDT 2014

danaholmes911

RT @brendanweiss @mtmdphd Yes would stop chemo #mmsm

Sun Jun 29 18:30:29 PDT 2014

amyloid_planet

@kat4gators @brendanweiss agree. Rx plan not based on cyto in #amyloidosis #mmsm

Sun Jun 29 18:30:34 PDT 2014

danaholmes911

RT @Amyloid_Planet @kat4gators @brendanweiss agree. Rx plan not based on cyto in #amyloidosis #mmsm

Sun Jun 29 18:30:43 PDT 2014

mtmdphd

RT @Amyloid_Planet @kat4gators @brendanweiss agree. Rx plan not based on cyto in #amyloidosis #mmsm

Sun Jun 29 18:30:52 PDT 2014

danaholmes911

Does treating #amyloidosis eradicate the clone? #mmsm

Sun Jun 29 18:31:13 PDT 2014

mtmdphd

@Amyloid_Planet @kat4gators @brendanweiss I think no "biomarkers" to guide Rx. Still a tough disease #mmsm

Sun Jun 29 18:31:13 PDT 2014

myelomateacher

Any clinical trials for #AL ? #MMSM

Sun Jun 29 18:31:27 PDT 2014

brendanweiss

@MyelomaTeacher MLN9708 (ixazomib)+ dex v. doctor's choice in relapsed AL <http://t.co/yPvOOpU3Ib> #mmsm

Sun Jun 29 18:31:57 PDT 2014

- amyloid_planet** @mtmdphd no proven role for maintenance in #amyloidosis ..important, as even lower intensity Rx may have signif tox in this pt pop #mmsm
Sun Jun 29 18:31:59 PDT 2014
- mtmdphd** @MyelomaTeacher Tough to get organized with new Rx and small volume disease. Open to disruption... #mmsm
Sun Jun 29 18:32:04 PDT 2014
- mtmdphd** @Amyloid_Planet right. Thanks #mmsm
Sun Jun 29 18:32:16 PDT 2014
- brendanweiss** Carfilzomib + dex in previously treated AL #amyloidosis <http://t.co/mDKWbNA8uz> #mmsm
Sun Jun 29 18:32:21 PDT 2014
- mtmdphd** RT @brendanweiss @MyelomaTeacher MLN9708 (ixazomib)+ dex v. doctor's choice in relapsed AL <http://t.co/oPPoOzjtOk> #mmsm
Sun Jun 29 18:32:28 PDT 2014
- danaholmes911** RT @brendanweiss @MyelomaTeacher MLN9708 (ixazomib)+ dex v. doctor's choice in relapsed AL <http://t.co/v3GTkg3Wpy> #mmsm
Sun Jun 29 18:32:42 PDT 2014
- mtmdphd** T2 - What are the most promising therapies in trials or other? #mmsm
Sun Jun 29 18:32:54 PDT 2014
- brendanweiss** A monoclonal antibody NEOD001 targeting amyloid deposits in patients with AL <http://t.co/PtjBnaVAkm> #mmsm
Sun Jun 29 18:32:54 PDT 2014
- danaholmes911** RT @brendanweiss A monoclonal antibody NEOD001 targeting amyloid deposits in patients with AL <http://t.co/lpWzfDR7VZ> #mmsm
Sun Jun 29 18:33:09 PDT 2014
- myelomateacher** If a patient develops #AL should they seek advise from an #AL specialist or can any myeloma specialist treat AL #MMSM
Sun Jun 29 18:33:10 PDT 2014
- mtmdphd** @brendanweiss Great. this tweet overlapped with my query #mmsm
Sun Jun 29 18:33:15 PDT 2014
- brendanweiss** @mtmdphd For AL the next wave of therapies will target amyloid deposits #mmsm
Sun Jun 29 18:33:24 PDT 2014
- myelomateacher** RT @mtmdphd: RT @brendanweiss @MyelomaTeacher MLN9708 (ixazomib)+ dex v. doctor's choice in relapsed AL <http://t.co/oPPoOzjtOk> #mmsm
Sun Jun 29 18:33:25 PDT 2014

mtmdphd

RT @brendanweiss @mtmdphd For AL the next wave of therapies will target amyloid deposits #mmsm

Sun Jun 29 18:33:35 PDT 2014

amyloid_planet

@mtmdphd carfilzomib being studied now by @CohenAd_MMdoc for pts w prev treated #amyloidosis #mmsm

Sun Jun 29 18:33:44 PDT 2014

danaholmes911

@brendanweiss Is NEOD001 showing promise in targeting amyloid in all organs? #mmsm

Sun Jun 29 18:34:03 PDT 2014

danaholmes911

RT @Amyloid_Planet @mtmdphd carfilzomib being studied now by @CohenAd_MMdoc for pts w prev treated #amyloidosis #mmsm

Sun Jun 29 18:34:15 PDT 2014

brendanweiss

@DanaHolmes911 @brendanweiss It is too early to tell #mmsm

Sun Jun 29 18:34:22 PDT 2014

mtmdphd

@brendanweiss Very interesting. Only a few sites. Not common. But my health system big. Will track this... T2 #mmsm

Sun Jun 29 18:34:38 PDT 2014

brendanweissDoxycycline (an antibiotic) reduces fibril formation in mice <http://t.co/TfMLYCPHoF> #mmsm

Sun Jun 29 18:34:43 PDT 2014

danaholmes911

RT @mtmdphd RT @brendanweiss @mtmdphd For AL the next wave of therapies will target amyloid deposits #mmsm

Sun Jun 29 18:34:51 PDT 2014

brendanweissDoxycycline is being used in an ongoing trial for AL <http://t.co/6TgoR5NikB> #mmsm

Sun Jun 29 18:34:51 PDT 2014

mtmdphd

@brendanweiss Wow #mmsm

Sun Jun 29 18:34:52 PDT 2014

brendanweissClinical trials overview from Amyloidosis Support Groups <http://t.co/8hpcf1GU5X> #mmsm

Sun Jun 29 18:35:15 PDT 2014

danaholmes911RT @brendanweiss Carfilzomib + dex in previously treated AL #amyloidosis <http://t.co/pPLBm0nWZr> #mmsm

Sun Jun 29 18:35:17 PDT 2014

mtmdphd

@brendanweiss Reminds me of MM BiRD regimen w/ abx. (diff MOA) #mmsm

Sun Jun 29 18:35:29 PDT 2014

- myelomateacher** So it seems to me the same drugs are used to treat #AL and #myeloma #mmsm
Sun Jun 29 18:35:33 PDT 2014
- hskulkarni** Great resource "@brendanweiss: Amyloidosis awareness book for patients and their caregivers <http://t.co/YMMRLbv7Dv> #mmsm"
Sun Jun 29 18:35:33 PDT 2014
- danaholmes911** RT @brendanweiss Doxycycline is being used in an ongoing trial for AL <http://t.co/457Z7GikJ0> #mmsm
Sun Jun 29 18:35:46 PDT 2014
- mtmdphd** @hskulkarni TY for joining #mmsm
Sun Jun 29 18:35:51 PDT 2014
- myelomateacher** RT @brendanweiss: Doxycycline is being used in an ongoing trial for AL <http://t.co/6TgoR5NikB> #mmsm
Sun Jun 29 18:35:51 PDT 2014
- danaholmes911** RT @brendanweiss Doxycycline (an antibiotic) reduces fibril formation in mice <http://t.co/6oJHkMD47J> #mmsm
Sun Jun 29 18:35:54 PDT 2014
- brendanweiss** @Amyloid_Planet any thoughts on green tea extract? #mmsm
Sun Jun 29 18:35:58 PDT 2014
- mtmdphd** @brendanweiss @Amyloid_Planet Tait Shanalet showed activity in CLL. Not sure about MM or amyloidosis? #mmsm
Sun Jun 29 18:36:25 PDT 2014
- dannysparker** 4 yr #MM patient, sCR post SCT for 3.5 yrs. Just developed low-level Bence-Jones proteins. Differential diagnosis? #MMSM
Sun Jun 29 18:36:27 PDT 2014
- mtmdphd** @dannysparker s/p Auto SCT may develop new non-same M-proteins - heavy or light. Doesn't nec mean amyloid. But good to query... #mmsm
Sun Jun 29 18:37:16 PDT 2014
- danaholmes911** @Amyloid_Planet @brendanweiss Can AL #amyloid treatment eradicate the clone? #mmsm
Sun Jun 29 18:37:24 PDT 2014
- brendanweiss** @dannysparker were the B-J proteins present at diagnosis? do you have light chain myeloma? #mmsm
Sun Jun 29 18:37:28 PDT 2014
- danaholmes911** RT @brendanweiss @Amyloid_Planet any thoughts on green tea extract? #mmsm
Sun Jun 29 18:38:01 PDT 2014

- mtmdphd** T2 - Phase I, Open Label, Dose Escalation Study of NEOD001 in Subjects With Light Chain (AL) Amyloidosis <http://t.co/azV6xzKPD6> #mmsm
Sun Jun 29 18:38:21 PDT 2014
- danaholmes911** RT @mtmdphd T2-Phase I,Open Label, Dose Escalation Study of NEOD001 in Subjects With Light Chain(AL)Amyloidosis <http://t.co/qnGJDp4MLZ> #mmsm
Sun Jun 29 18:39:02 PDT 2014
- myelomateacher** RT @mtmdphd: T2 - Phase I, Open Label, Dose Escalation Study of NEOD001 in Subjects With Light Chain (AL) Amyloidosis <http://t.co/azV6xzKPD...>
Sun Jun 29 18:39:22 PDT 2014
- mtmdphd** Do we have a separate hashtag for amyloidosis ? Will query: @subatomicdoc ... #mmsm
Sun Jun 29 18:39:46 PDT 2014
- myelomateacher** What's light chain #AL ? #MMSM
Sun Jun 29 18:40:10 PDT 2014
- brendanweiss** @mtmdphd @subatomicdoc #amyloidosis #mmsm
Sun Jun 29 18:40:17 PDT 2014
- drjhoffmanmiami** @brendanweiss @Amyloid_Planet may interfere with effects of velcade, this needs to be remembered #mmsm
Sun Jun 29 18:40:20 PDT 2014
- mtmdphd** @Drjhoffmanmiami True. Green tea --- needs to be MD driven and/or Pt tell MD ! #mmsm
Sun Jun 29 18:40:54 PDT 2014
- dannysparker** @brendanweiss Not present @ diagnosis. Then: serum expression of monoclonal protein till CR; nothing now in SPEP. Jun:4mg/24 n UPEP #mmsm
Sun Jun 29 18:41:05 PDT 2014
- brendanweiss** @Drjhoffmanmiami @Amyloid_Planet Thanks for joining, yes this is important - I mention to all my patients #mmsm
Sun Jun 29 18:41:13 PDT 2014
- mtmdphd** Green Tea Polyphenol Epigallocatechin Gallate (EGCG) Antagonizes Inhibit Effect of Bortezomib on #Myeloma ASH07 <http://t.co/ijfBnvqoLo> #mmsm
Sun Jun 29 18:41:16 PDT 2014
- mtmdphd** Green tea polyphenols block anticancer effects of bortezomib & other boronic acid-based proteasome inhibitors <http://t.co/Ztxjcwacff> #mmsm
Sun Jun 29 18:41:26 PDT 2014
- danaholmes911** @brendanweiss Also heard of 2nd amyloid target - MU11-1F4 @ recent Amyloid meeting. #mmsm
Sun Jun 29 18:41:43 PDT 2014

- mtmdphd** "...our results strongly suggest that patients undergoing bortezomib therapy avoid green tea products." <http://t.co/bDHJfXsR4e> #mmsm
Sun Jun 29 18:41:46 PDT 2014
- brendanweiss** @dannysparker if at that low level likely not significant, but would need more data #mmsm
Sun Jun 29 18:41:55 PDT 2014
- myelomateacher** RT @mtmdphd: Green tea polyphenols block anticancer effects of bortezomib & other boronic acid-based proteasome inhibitors <http://t.co/Ztxj...>
Sun Jun 29 18:42:16 PDT 2014
- mtmdphd** @Drjhoffmanmiami TY for joining #mmsm
Sun Jun 29 18:42:18 PDT 2014
- amyloid_planet** @Drjhoffmanmiami @brendanweiss agree was just about to type same. No green tea w velcade #amyloidosis #mmsm
Sun Jun 29 18:43:02 PDT 2014
- danaholmes911** RT @Amyloid_Planet @Drjhoffmanmiami @brendanweiss agree was just about to type same. No green tea w velcade #amyloidosis #mmsm
Sun Jun 29 18:43:17 PDT 2014
- myelomateacher** RT @DanaHolmes911: @brendanweiss Also heard of 2nd amyloid target - MU11-1F4 @ recent Amyloid meeting. #mmsm
Sun Jun 29 18:43:23 PDT 2014
- danaholmes911** RT @Drjhoffmanmiami @brendanweiss @Amyloid_Planet may interfere with effects of velcade, this needs to be remembered #mmsm
Sun Jun 29 18:43:52 PDT 2014
- brendanweiss** @DanaHolmes911 Yes - this is for imaging of #amyloidosis deposits - not clear if this would also have a therapeutic benefit #mmsm
Sun Jun 29 18:43:54 PDT 2014
- danaholmes911** RT @brendanweiss @DanaHolmes911 Yes-this is for imaging of #amyloidosis deposits-not clear if this wud also have a therapeutic benefit #mmsm
Sun Jun 29 18:44:36 PDT 2014
- mtmdphd** T3 - Future directions (in #Amyloidosis Dx / Staging / Tx) #mmsm
Sun Jun 29 18:44:49 PDT 2014
- vincentrk** Sorry. Joining late #mmsm
Sun Jun 29 18:44:58 PDT 2014
- brendanweiss** T3- Early detection remains critical for all forms of amyloidosis, but especially AL #mmsm
Sun Jun 29 18:45:23 PDT 2014

- danaholmes911** Why no SAP scan in U.S. centers ? #mmsm
Sun Jun 29 18:45:24 PDT 2014
- danaholmes911** RT @brendanweiss T3- Early detection remains critical for all forms of amyloidosis, but especially AL #mmsm
Sun Jun 29 18:45:33 PDT 2014
- myelomateacher** @VincentRK Welcome #mmsm
Sun Jun 29 18:45:44 PDT 2014
- brendanweiss** T3- Early detection is possible - amyloidogenic light chains precede AL for many years (paper forthcoming) <http://t.co/IVFqxU12mL> #mmsm
Sun Jun 29 18:45:56 PDT 2014
- mtmdphd** @VincentRK Great to hear/see you #mmsm
Sun Jun 29 18:45:59 PDT 2014
- brendanweiss** @VincentRK welcome #mmsm
Sun Jun 29 18:46:06 PDT 2014
- mtmdphd** T3 Future directions #mmsm
Sun Jun 29 18:46:16 PDT 2014
- vincentrk** Not sure we need SAP scan for deciding or monitoring therapy in AL amyloidosis #mmsm
Sun Jun 29 18:46:19 PDT 2014
- dannysparker** @brendanweiss Here is FLC & FLCR recent history; Kappa just went hi #mmsm Early sign of relapse? Or other? #mmsm <http://t.co/qRcqS3wXPF>
Sun Jun 29 18:46:36 PDT 2014
- vincentrk** Thanks @brendanweiss #mmsm
Sun Jun 29 18:46:38 PDT 2014
- mtmdphd** T3 MT @brendanweiss Early detection is possible - amyloidogenic light chains precede AL for many years (...) <http://t.co/cbLjMmoLWo> #mmsm
Sun Jun 29 18:46:43 PDT 2014
- myelomateacher** RT @brendanweiss: T3- Early detection remains critical for all forms of amyloidosis, but especially AL #mmsm
Sun Jun 29 18:46:53 PDT 2014
- brendanweiss** @VincentRK Agree utility seems low, can't detect cardiac disease #mmsm
Sun Jun 29 18:47:04 PDT 2014

- danaholmes911** @VincentRK @brendanweiss @ Amyloid_Planet wouldn't SAP scan allow for "easier" discovery ? #mmsm
Sun Jun 29 18:47:25 PDT 2014
- danaholmes911** RT @brendanweiss @VincentRK Agree utility seems low, can't detect cardiac disease #mmsm
Sun Jun 29 18:47:43 PDT 2014
- myelomateacher** @VincentRK What's SAP ? #MMSM
Sun Jun 29 18:47:45 PDT 2014
- imfmyeloma** RT @mtmdphd: T3 MT @brendanweiss Early detection is possible - amyloidogenic light chains precede AL for many years (...) <http://t.co/cbLjM...>
Sun Jun 29 18:47:54 PDT 2014
- danaholmes911** @brendanweiss @VincentRK SAP scan Q overlapped with your response. #mmsm
Sun Jun 29 18:48:26 PDT 2014
- mtmdphd** RT @VincentRK Not sure we need SAP scan for deciding or monitoring therapy in AL amyloidosis #mmsm
Sun Jun 29 18:48:33 PDT 2014
- scarlett_0hara** RT @mtmdphd: Green tea polyphenols block anticancer effects of bortezomib & other boronic acid-based proteasome inhibitors <http://t.co/Ztxj...>
Sun Jun 29 18:48:48 PDT 2014
- scarlett_0hara** RT @mtmdphd: Green Tea Polyphenol Epigallocatechin Gallate (EGCG) Antagonizes Inhibit Effect of Bortezomib on #Myeloma ASH07 <http://t.co/ij...>
Sun Jun 29 18:48:52 PDT 2014
- danaholmes911** RT @VincentRK Not sure we need SAP scan for deciding or monitoring therapy in AL amyloidosis #mmsm
Sun Jun 29 18:48:55 PDT 2014
- brendanweiss** @dannysparker are you on maintenance therapy with lenalidomide? #mmsm
Sun Jun 29 18:49:07 PDT 2014
- vincentrk** SAP scan uses one of the proteins commonly found in all forms of amyloid to detect location/extent of amyloid (purportedly) #mmsm
Sun Jun 29 18:49:15 PDT 2014
- mtmdphd** ECOG-ACRIN EA1A11 - VRd vs CfRd -> Len maint (2yr vs indefinite) <http://t.co/goIM8gy1rF> NCT01863550 <http://t.co/AgMXEZzGwW> #mmsm #EAOnC
Sun Jun 29 18:49:21 PDT 2014
- myelomateacher** Is there a printed checklist for symptoms of #amyloidosis that patients can use? #MMSM
Sun Jun 29 18:49:36 PDT 2014

- dannysparker** @mtmdphd @brendanweiss Could serum expression be lagging? Or could this be development of light chain #MM? #MMSM
Sun Jun 29 18:49:47 PDT 2014
- mtmdphd** MT @VincentRK SAP scan uses 1 of proteins commonly found in all forms of amyloid to detect location/extent of amyloid (purportedly) #mmsm
Sun Jun 29 18:49:56 PDT 2014
- brendanweiss** @dannysparker @mtmdphd the levels are very, very low and the ratio is near normal so I doubt this is a significant finding #mmsm
Sun Jun 29 18:50:39 PDT 2014
- myelomateacher** RT @VincentRK: SAP scan uses one of the proteins commonly found in all forms of amyloid to detect location/extent of amyloid (purportedly) ...
Sun Jun 29 18:50:49 PDT 2014
- mtmdphd** SAP scintigraphy <http://t.co/g3bypWoqPZ> #mmsm T2 T3
Sun Jun 29 18:50:50 PDT 2014
- danaholmes911** @brendanweiss @VincentRK Can local amyloid develop in soft tissue in treated systemic AL w/ normal range FLC ? #mmsm
Sun Jun 29 18:51:11 PDT 2014
- vincentrk** Our treatment approach for AL amyloid at Mayo Clinic <http://t.co/xrG9fVaieS> #mmsm
Sun Jun 29 18:51:36 PDT 2014
- brendanweiss** @MyelomaTeacher Amyloidosis awareness book for patients and their caregivers <http://t.co/byWEB4oPiF> #mmsm
Sun Jun 29 18:51:37 PDT 2014
- dannysparker** @brendanweiss Yes, Rev 10 mg/d 3 wk cycle for 2 yrs; then 5 mg/d because of neutropenia &URI; now back on 10 mg #mmsm
Sun Jun 29 18:51:54 PDT 2014
- kat4gators** Thoughts on lenalidomide maintenance in AL pts with CR? #mmsm
Sun Jun 29 18:52:06 PDT 2014
- myelomateacher** @brendanweiss Thanks! #MMSM
Sun Jun 29 18:52:13 PDT 2014
- mtmdphd** RT @VincentRK Our treatment approach for AL amyloid at Mayo Clinic <http://t.co/pdCHpi6fcS> #mmsm
Sun Jun 29 18:52:17 PDT 2014
- mtmdphd** RT @brendanweiss @MyelomaTeacher Amyloidosis awareness book for patients and their caregivers <http://t.co/u3ZQcp4XMN> #mmsm
Sun Jun 29 18:52:27 PDT 2014

brendanweiss

@kat4gators no data on maintenance in AL #mmsm

Sun Jun 29 18:52:30 PDT 2014

myelomateacherRT @VincentRK: Our treatment approach for AL amyloid at Mayo Clinic <http://t.co/xrG9fVaieS> #mmsm

Sun Jun 29 18:52:44 PDT 2014

vincentrk

Agree with @brendanweiss on maintenance #mmsm

Sun Jun 29 18:52:46 PDT 2014

mtmdphd

RT @VincentRK Agree with @brendanweiss on maintenance #mmsm

Sun Jun 29 18:52:54 PDT 2014

danaholmes911

RT @brendanweiss @kat4gators no data on maintenance in AL #mmsm

Sun Jun 29 18:52:55 PDT 2014

danaholmes911

RT @VincentRK Agree with @brendanweiss on maintenance #mmsm

Sun Jun 29 18:53:04 PDT 2014

mtmdphd

T3 - What is biggest #amyloidosis clinical question addressable by a trial now? #mmsm

Sun Jun 29 18:53:20 PDT 2014

myelomateacher

RT @brendanweiss: @kat4gators no data on maintenance in AL #mmsm

Sun Jun 29 18:53:36 PDT 2014

danaholmes911

@mtmdphd T3 can it be cured? #mmsm

Sun Jun 29 18:53:54 PDT 2014

kat4gators

@brendanweiss Know any practitioners who've done it? #mmsm

Sun Jun 29 18:53:58 PDT 2014

brendanweiss

@mtmdphd the biggest question may be can we even do a trial! Disease is rare, patients very heterogeneous - @VincentRK - thoughts? #mmsm

Sun Jun 29 18:54:15 PDT 2014

brendanweiss

@kat4gators I am not aware of any #mmsm

Sun Jun 29 18:54:41 PDT 2014

mtmdphd

RT @brendanweiss: @mtmdphd the biggest question may be can we even do a trial! Disease is rare, patients very heterogeneous - @VincentRK - ...

Sun Jun 29 18:54:54 PDT 2014

myelomateacher

RT @brendanweiss: @mtmdphd the biggest question may be can we even do a trial! Disease is rare, patients very heterogeneous - @VincentRK - ...

Sun Jun 29 18:55:45 PDT 2014

llsadvocacy

RT @mtmdphd: To "join" the #mmsm Twitter discussion you can just search #mmsm & follow feed on Twitter or HootSuite or use <http://t.co/sCnB...>

Sun Jun 29 18:55:48 PDT 2014

brendanweiss

@DanaHolmes911 @mtmdphd HDT has led to very long survival in AL <http://t.co/XQsDfomFhT> #mmsm

Sun Jun 29 18:55:49 PDT 2014

vincentrk

Right now we have sort of moved into bortezomib based initial therapy without a phase III. Problem is AL is rare-hard to do one #mmsm

Sun Jun 29 18:55:53 PDT 2014

vincentrk

Similarly we are offering transplant to eligible pts in absence of phase III data in AL. #mmsm

Sun Jun 29 18:56:14 PDT 2014

mtmdphd

About 5 min left. Want to wrap up with take home messages and URL links for more info? #mmsm

Sun Jun 29 18:56:17 PDT 2014

mtmdphd

RT @VincentRK Similarly we are offering transplant to eligible pts in absence of phase III data in AL. #mmsm

Sun Jun 29 18:56:24 PDT 2014

danaholmes911

RT @brendanweiss: @DanaHolmes911 @mtmdphd We are doing this study @PennCancer <http://t.co/mDKWbNA8uz> #mmsm

Sun Jun 29 18:56:29 PDT 2014

brendanweiss

Help is available!!! Amyloidosis centers around the US from the Amyloidosis Support Groups <http://t.co/8hpcflGU5X> #mmsm

Sun Jun 29 18:56:44 PDT 2014

vincentrk

I guess the next big question would be optimal treatment of patients who do not achieve the desired response with current rx #mmsm

Sun Jun 29 18:56:50 PDT 2014

mtmdphd

MT @VincentRK Right now we have sort of moved into bortezomib based initial Rx w/o a phase III. Problem is AL is rare-hard to do 1 #mmsm

Sun Jun 29 18:56:52 PDT 2014

brendanweiss

Diagnosis can be very challenging - patients should seek out experts <http://t.co/81LoNMGxq6> #mmsm

Sun Jun 29 18:56:56 PDT 2014

mtmdphd

RT @brendanweiss Help is available!!! Amyloidosis centers around the US from the Amyloidosis Support Groups <http://t.co/U2u0nHLkk7> #mmsm

Sun Jun 29 18:57:03 PDT 2014

- mtmdphd** @VincentRK Started cardiac amyloid Pt on PCP - Pom Ctx Pred after progression. Limited data here. #mmsm
Sun Jun 29 18:57:32 PDT 2014
- mtmdphd** RT @brendanweiss Diagnosis can be very challenging - patients should seek out experts <http://t.co/Maih2eY6ES> #mmsm
Sun Jun 29 18:57:39 PDT 2014
- danaholmes911** RT @brendanweiss @DanaHolmes911 @mtmdphd HDT has led to very long survival in AL <http://t.co/e450TfDpdG> #mmsm
Sun Jun 29 18:57:42 PDT 2014
- vincentrk** So we are targeting FLC level <4 mg/dL as a treatment goal. Question is if frontline doesn't achieve that- whats next #mmsm
Sun Jun 29 18:57:43 PDT 2014
- myelomateacher** My head is spinning! I think a need to read that handbook Obviously I don't know much abt #amyloisosis #MMSM
Sun Jun 29 18:57:54 PDT 2014
- mtmdphd** @brendanweiss TY for being one of those engageable online experts! #mmsm
Sun Jun 29 18:58:02 PDT 2014
- danaholmes911** RT @mtmdphd @brendanweiss TY for being one of those engageable online experts! #mmsm
Sun Jun 29 18:58:13 PDT 2014
- mtmdphd** RT @MyelomaTeacher My head is spinning! I think a need to read that handbook Obviously I don't know much abt #amyloisosis #MMSM
Sun Jun 29 18:58:17 PDT 2014
- brendanweiss** @VincentRK Yes, a second line study would be interesting, but also challenging given experience with MLN9708 #mmsm
Sun Jun 29 18:58:19 PDT 2014
- vincentrk** Other trials involve Rx not directed at AL per se. Like role of AICDs routinely in high risk AL. Studied but not well.. yet #mmsm
Sun Jun 29 18:58:24 PDT 2014
- mtmdphd** #MMSM Hashtag Influencers, Transcript & Analytics #hcsml <http://t.co/Mrcnn3LyRG> via @simplur
Sun Jun 29 18:58:29 PDT 2014
- dannysparker** @brendanweiss @mtmdphd Echoes my UCSF meyloma doc: no big reason for concern at this point. 3.5 yrs post SCT w/CR. Plan:monitor FLCr #mmsm
Sun Jun 29 18:58:34 PDT 2014

- danaholmes911** RT @VincentRK So we are targeting FLC level <4 mg/dL as a treatment goal. Question is if frontline doesn't achieve that- whats next #mmsm
Sun Jun 29 18:58:42 PDT 2014
- kat4gators** I've kept a blog of my journey with #amyloidosis Would love to help any new dx. My life is back to normal. <http://t.co/6kMCB6mEAA> #mmsm
Sun Jun 29 18:58:51 PDT 2014
- brendanweiss** @DanaHolmes911 @mtmdphd I appreciate the feedback #mmsm
Sun Jun 29 18:58:52 PDT 2014
- myelomateacher** @brendanweiss How do we find experts? #MMSM
Sun Jun 29 18:59:02 PDT 2014
- vincentrk** Agree @brendanweiss. AL is really challenging from trial standpoint. At least in USA #mmsm
Sun Jun 29 18:59:06 PDT 2014
- amyloid_planet** @VincentRK newer regimens not having much impact on early mortality in #amyloidosis despite higher resp rates. trials needed #mmsm
Sun Jun 29 18:59:14 PDT 2014
- mtmdphd** @kat4gators Thanks. Glad to hear it. #mmsm
Sun Jun 29 18:59:21 PDT 2014
- myelomateacher** RT @VincentRK: Other trials involve Rx not directed at AL per se. Like role of AICDs routinely in high risk AL. Studied but not well.. yet ...
Sun Jun 29 18:59:24 PDT 2014
- brendanweiss** @kat4gators thanks for sharing #mmsm
Sun Jun 29 18:59:30 PDT 2014
- vincentrk** After all we in @eaonc could not accrue to a simple MD vs MD plus velcade trial #mmsm
Sun Jun 29 18:59:36 PDT 2014
- danaholmes911** RT @VincentRK After all we in @eaonc could not accrue to a simple MD vs MD plus velcade trial #mmsm
Sun Jun 29 18:59:46 PDT 2014
- myelomateacher** RT @VincentRK: Agree @brendanweiss. AL is really challenging from trial standpoint. At least in USA #mmsm
Sun Jun 29 18:59:56 PDT 2014
- mtmdphd** @dannysparker @brendanweiss Good. hard to respond to Pt specific queries in a fast 140 character format. Local MD knows U. #mmsm
Sun Jun 29 19:00:09 PDT 2014

brendanweiss

@VincentRK Yes, need a translational approach to advanced cardiac AL #mmsm

Sun Jun 29 19:00:19 PDT 2014

vincentrk

I agree. @amyloid_planet. I do not think we can reduce early deaths by improving therapy targeting PCs though #mmsm

Sun Jun 29 19:00:23 PDT 2014

mtmdphd

RT @VincentRK Agree @brendanweiss. AL is really challenging from trial standpoint. At least in USA #mmsm

Sun Jun 29 19:00:23 PDT 2014

vincentrk

The cause of early death is due to damage already done in the myocardium and conducting system. Needs a different strategy #mmsm

Sun Jun 29 19:00:49 PDT 2014

myelomateacher

Thanks everyone for givig up an hour of your weekend! You rock. #MMSM

Sun Jun 29 19:01:01 PDT 2014

danaholmes911

@brendanweiss AL seems so very challenging to diagnose upfront, is it misdiagnosed often? what to do ? How do you solve? #mmsm

Sun Jun 29 19:01:11 PDT 2014

brendanweiss

@VincentRK @amyloid_planet I agree!!! #mmsm

Sun Jun 29 19:01:12 PDT 2014

mtmdphd

It' s 9:00p CT. Thank you all for participating! The lurkers are much higher than posts, so many people benefit from this! Thanks. #mmsm

Sun Jun 29 19:01:19 PDT 2014

brendanweiss

@DanaHolmes911 Yes, frequently #mmsm

Sun Jun 29 19:01:27 PDT 2014

mtmdphd

@MyelomaTeacher Co-instigator! #mmsm

Sun Jun 29 19:01:33 PDT 2014

vincentrk

Thanks as usual @mtmdphd for organizing. #mmsm

Sun Jun 29 19:01:47 PDT 2014

mtmdphd

MT @VincentRK Cause of early death is due to damage already done in the myocardium and conducting system. Needs a different strategy #mmsm

Sun Jun 29 19:01:50 PDT 2014

mtmdphd

@VincentRK I've got Dr. Tajik here now to help me out. :) #mmsm

Sun Jun 29 19:02:08 PDT 2014

danaholmes911

One of the best chats ever ! @brendanweiss @mtmdphd #mmsm

Sun Jun 29 19:02:09 PDT 2014

danaholmes911

RT @VincentRK Thanks as usual @mtmdphd for organizing. #mmsm

Sun Jun 29 19:02:26 PDT 2014

brendanweiss

Thanks to @mtmdphd for organizing and everyone for sharing their thoughts #mmsm

Sun Jun 29 19:02:30 PDT 2014

danaholmes911

RT @brendanweiss Thanks to @mtmdphd for organizing and everyone for sharing their thoughts #mmsm

Sun Jun 29 19:02:35 PDT 2014

mtmdphd

@DanaHolmes911 TY. Due to @brendanweiss super informed and prepared. #PassionAmyloid #mmsm

Sun Jun 29 19:02:38 PDT 2014

vincentrk

Wow. Can you please convey my best to Dr. Tajik. He is the best #mmsm

Sun Jun 29 19:02:40 PDT 2014

danaholmes911

RT @mtmdphd @DanaHolmes911 TY. Due to @brendanweiss super informed and prepared. #PassionAmyloid #mmsm

Sun Jun 29 19:02:45 PDT 2014

vincentrk

@mtmdphd Wow. Can you please convey my best to Dr. Tajik. He is the best #mmsm

Sun Jun 29 19:02:56 PDT 2014

myelomateacher

RT @mtmdphd: It's 9:00p CT. Thank you all for participating! The lurkers are much higher than posts, so many people benefit from this! Tha...

Sun Jun 29 19:02:59 PDT 2014

danaholmes911

@mtmdphd @brendanweiss Agreed ! #mmsm

Sun Jun 29 19:03:01 PDT 2014

mtmdphd

@VincentRK Good guy to have to review cardiac amyloid! Will need to have you come visit some day. #mmsm

Sun Jun 29 19:03:12 PDT 2014

mtmdphd

@brendanweiss TY #mmsm

Sun Jun 29 19:03:36 PDT 2014

myelomateacher

RT @VincentRK: The cause of early death is due to damage already done in the myocardium and conducting system. Needs a different strategy #...

Sun Jun 29 19:03:45 PDT 2014

kat4gators

@mtmdphd @VincentRK @brendanweiss @Amyloid_Planet I will try to create transcript for posting on Amyloidosis Support Group site. #mmsm

Sun Jun 29 19:04:01 PDT 2014

brendanweiss

@mtmdphd My pleasure #mmsm

Sun Jun 29 19:04:08 PDT 2014

mtmdphd

RT @kat4gators: @mtmdphd @VincentRK @brendanweiss @Amyloid_Planet I will try to create transcript for posting on Amyloidosis Support Group ...

Sun Jun 29 19:04:33 PDT 2014

mtmdphd

July #mmsm TweetChat --> 7/27 8-9pm CT w/ @DrOlaLandgren Topic: Minimal Residual Disease (MRD) in Multiple Myeloma

Sun Jun 29 19:05:05 PDT 2014

mtmdphd

#mmsm - This hour kind of blew by. may need to re-visit Amyloidosis topic in the future. Thanks much to @brendanweiss !

Sun Jun 29 19:05:08 PDT 2014

danaholmes911

RT @mtmdphd #mmsm - This hour kind of blew by. may need to re-visit Amyloidosis topic in the future. Thanks much to @brendanweiss !

Sun Jun 29 19:05:12 PDT 2014

kat4gators

Thanks to all!! Appreciate your time @brendanweiss @mtmdphd @Amyloid_Planet @VincentRK #mmsm

Sun Jun 29 19:05:23 PDT 2014

myelomateacher

RT @mtmdphd: @DanaHolmes911 TY. Due to @brendanweiss super informed and prepared. #PassionAmyloid #mmsm

Sun Jun 29 19:05:24 PDT 2014

danaholmes911

@mtmdphd @brendanweiss Amazing what one can learn in 1 hour ! Thanks so much to all who contributed to our continuing education ! #mmsm

Sun Jun 29 19:05:54 PDT 2014

amyloid_planet

"@kat4gators: Thanks to all!! Appreciate your time @brendanweiss @mtmdphd @Amyloid_Planet @VincentRK #mmsm" thanks all.

Sun Jun 29 19:05:54 PDT 2014

mtmdphd

Thanks all! Signing off...until next month... #mmsm

Sun Jun 29 19:06:23 PDT 2014

dannysparker

@mtmdphd @brendanweiss Sorry 2 put u on spot; Still, appreciate input! Was confused by lo-level B-J proteins w/o serum. Thanks a lot. #mmsm

Sun Jun 29 19:06:35 PDT 2014

myelomateacher

RT @DanaHolmes911: @mtmdphd @brendanweiss Amazing what one can learn in 1 hour ! Thanks so much to all who contributed to our continuing ed...

Sun Jun 29 19:06:43 PDT 2014

myelomateacher

RT @mtmdphd: July #mmsm TweetChat --> 7/27 8-9pm CT w/ @DrOlaLandgren Topic: Minimal Residual Disease (MRD) in Multiple Myeloma

Sun Jun 29 19:07:10 PDT 2014

danaholmes911

RT @brendanweiss @DanaHolmes911 Yes, frequently #mmsm

Sun Jun 29 19:07:15 PDT 2014

siewlee18

RT @mtmdphd: MT @VincentRK Cause of early death is due to damage already done in the myocardium and conducting system. Needs a different st...

Sun Jun 29 19:07:26 PDT 2014

mtmdphd

The numbers: 32 Participants. 914,930 Impressions. More #MMSM analytics here: <http://t.co/wvhQvSnQF3> via @symplur

Sun Jun 29 19:07:47 PDT 2014

danaholmes911

RT @mtmdphd July #mmsm TweetChat --> 7/27 8-9pm CT w/ @DrOlaLandgren Topic: Minimal Residual Disease (MRD) in Multiple Myeloma

Sun Jun 29 19:07:55 PDT 2014