Infectious Diseases Society of America
Emerging Infections Network

Comments for Query:
‘Pediatric Mycobacterium abscessus and Use of Clofazimine’

Comments made by 27 respondents.
State or province of practice shown in brackets, e.g., [CA]

Comments on M. abscessus and/or NTM in the setting of cystic fibrosis
• Most cases in CF with NTM have M. avium complex (MAC) in my pediatric experience, but we have seen a variety of NTM - some non-pathogenic in culture. Have to date not needed clofazimine, but would try to obtain if needed. P.S. We did have one patient with suspected NTM at one commercial lab who turned out to have Segniliparus rugosus at ARUP. Association in CF and Segniliparus rugosus (also + AFB) well documented. [GA]
• We need more data regarding the clinical sig of NTM in the setting of CF, esp if there is pulm decline: is it cause ir effect? If the meds help do they do so because of their anti-infective or anti-inflammatory properties? [IL]
• Most of our isolates are M. kansasii or MAI and a few M. marinum [CO]
• Pulmonary disease in CF has been complicated by recovery of multiple mycobacterial species. [AR]
• I have had several pts with MAC "colonization" vs disease. I usually consult Jeff Starke for the complicated patients - we recently discussed that I had no experience with clofazimine. [KY]
• It would appear that CF-related M. abscessus has increased at our institution. [TN]
• Pulmonologists manage the CF cases in our institute [NE]
• I recently treated a VP shunt infection with a combination of azithromycin, tigecycline and linezolid. The patient tolerated 4 months of therapy after shunt removal. I have tried tigecycline in some CF patients but have had to stop it because of side effects, mainly nausea and emesis. I have never had to use clofazimine. [OH]
• I did have a case but it was 8-10 years ago. I am not sure I can remember much in the way of details. So, I guess the answer is NA. [MN]
• I used amikacin, cefoxitin, clarithromycin and she is being maintained for the past 5-6 years on inhaled amikacin. We just had a new case this week [ON]

Comments about clofazimine
• We have used clofazimine. Unfortunately, therapies for M. abscessus in CF patients do not work. I have failed to "eradicate" the organism in most instances. [IN]
• No experience with CF; our pt is s/p BMT and onc wanted to use it for both the mycobacterium and GVH (for which it apparently has some activity). [CA]
• I prescribed clofazimine for a case of lepromatous leprosy treated 2010-2012 with refractory erythema nodosum leprosum. [OR]
• We have avoided using clofazimine. [VT]
• Was told that it would be too difficult to obtain clofazimine so did not go through the hoops to try [NC]
• We were considering trying to obtain clofazimine but did not, so we do not have a case to put into a series. However, I fully support this idea, and would participate if we have such a case. [KY]
• No experience with clofazimine [MA]
• Clofazimine not obtained for pt with M. abscessus, rather one with M. haemophilum [CA]
• We have now used clofazimine twice. Have been reasonably happy with side effect profile, though too early to know if it has been effective. [TN]
• I treated an adolescent with CF with resistant pulmonary NTM in 2005. I had to obtain clofazimine with an emergency IND and obtain compassionate use approval from our institutional IRB. The process was very involved. The adolescent completed the therapy without adverse effects, although I am not sure of her long term outcome as I departed the institution before she completed her therapy. [GA]
• I recently had a case of a CF patient with a MDR strain of M. abscessus that was sensitive to clofazimine. There was some history of drug allergy. I did not contact the CDC about obtaining it, since I was given the impression that it was reserved for MDR TB. I was able to come up with an acceptable drug regimen for now. [FL]
• We seriously discussed clofazimine for one patient but given difficulty in obtaining the drug and limited efficacy data, we did not pursue. [MD]
• Used clofazime once about 10 years ago. Child got the characteristic bronze color, but responded to the treatment. [CA]
• IDSA guidelines are a good resource. I have never tried to obtain clofazimine. [DC]
• For the single recent CF patient described above, we have decided to defer treatment but understand drug is available from Hansen Society. Did not attempt so unaware how complicated/successful this source would be. Patient has mutation amenable to new CF drug Kalydeco, so are trying this management first. Also asking Micro to pull all adult/pedi M abscessus for last 5 years for our review re pt age/CF status but those data not available in time for your deadline. [MI]
• We had no issues accessing clofazimine [TN]
• Our pulmonologists obtained the drug for one CF patient with M. abscessus from multiple sputums with clinical worsening. I am not familiar with the technicalities of getting the medication. [CA]
• We were consulted on a patient with CF and M. abscessus which the pulmonary physician had already placed on clofazimine. We continued this medication based on the severity of her disease. [CA]