### Patient and Caregiver Experience With Anti-VEGF Intravitreal Injections to Treat Neovascular Age-Related Macular Degeneration and Diabetic Macular Edema in the USA

64-73 57-77

35-77 50-90

7 (78) 13 (68)

3 (16)

3 (16)

0

1 (5)

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5-20 2-34

2-59

9 (100) 13 (68

7 (78) 9 (47)

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2 (22) 1 (5)

5 (56) 9 (47) Nancy M. Holekamp, MD<sup>1</sup>: Veeral S. Sheth, MD, MBA, FACS<sup>2</sup>: Murtaza K, Adam, MD<sup>3</sup>: Jérémy Lambert, PhD<sup>4</sup>: Hannah B. Lewis, PhD<sup>5</sup>; Ankit Pahwa, BE, MS<sup>6</sup>; Gloria C. Chi, PhD<sup>7</sup>; Brittany Gentile, PhD<sup>7</sup>; Vincent Garmo, MHS<sup>7</sup>;

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— DME (n = 67)

--- nAMD (n = 98)

#### **Key Clinical Question**

- What is the patient and caregiver anti-vascular endothelial growth factor intravitreal therapy (anti-VEGF IVT) for neovascular age-related macular degeneration (nAMD) and diabetic macular edema (DME)?
- This study aimed to assess treatment barriers and burden among patients and caregivers to identify where efforts should be directed to improve real-world outcomes with anti-VEGF therapy

#### Introduction

- that are associated with reduced functi health-related quality of life (HRQoL)<sup>1,2</sup>
- Anti-VEGF IVTs have been successful in improving and preserving vision and HRQoL for patients living with nAME or DME, but optimal outcomes require frequent treatmen
- caregivers, and the health care system, which affect patients' ability to follow their treatment management plan

#### Methods

- - Additional clinical data (eg. patient sociodemographic characteristics, geographical region, medical history, treatments recificulding anti-VEGF treatments], comorbidities, and visual acuity) were collected via medical chart extraction
- questions on the care recipient's clinical history and treatment experience, de novo questions about experiences and impacts of caregiving, and the Caregiver Reaction Assessment to measure caregiver burden and feelings associated with caregiving

#### **Conclusions**

- · Patients and caregivers reported impairment of daily activities, barriers, and burden linked to the anti-VEGF IVT management of nAMD and DME, despite the relatively high adherence and treatment satisfaction of patients
- · Caregivers devote significant time to caring for their recipient, with the greatest impact on caregiver schedule disruptions and absenteeism for those still working
- · More durable therapies, with longer treatment intervals and fewer clinic visits, could potentially alleviate the treatment burden and address current barriers experienced by patients and caregivers
- · Limitations: (1) Despite the efforts to enrich the population with "nonadherent" patients, the number of nonadherent patients was too low to explore treatment barriers and burden in this specific group; (2) Limited diversity in patient ethnicity/race, despite the efforts to include diverse sites in the study; (3) Caregiver sample size may be too limited to draw robust conclusions; (4) Patient and caregiver responses may be subject to recall and information bias

#### 1. Patient and Caregiver Characteristics

- Between January and August 2021, 67 patients with DME, 98 patients with nAMD, 9 caregivers of patients with DME, and 19 caregivers
- On average, patients with DME were younger than patients with nAMD and had better visual acuity recorded at the time of the survey
- The majority of caregivers of patients with DME were caring for their spouses/partners, whereas roughly half of caregivers of patients
- with nAMD were caring for spouses/partners and roughly half were caring for their parents (Table 1B)

Age, years

Q1-Q3

Female, n (%)

Minimum-maximum

Vorking status, n (%)

Unemployed, seeking work

I prefer not to answer

Divorced/separated

caregiver, n (%)

Spouse/partner

Mother or father

uncle, cousin)

Q1-Q3

Another family membe

Length of time as caregiver,

Minimum-maximum

Care recipient's relationship to

Looking after home or family

Working full-time

Working part-time

Self-employed

Retired

Student

Other

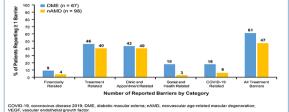
#### Table 1A. Patient Characteristics



#### 2. Anti-VEGF Treatment Barriers Reported by Patients

- As self-reported by patients, 12% of patients with DME (n = 8) and 3% of patients with nAMD (n = 3) missed
- About two-thirds of patients with DME (n = 41) and half of patients with nAMD (n = 46) reported ≥ 1 barrier to attending injection visits
- Reported barriers (Figure 1) were mainly related to treatment (eg., pain and discomfort, absence of treatment benefit), clinic and appointment factors (eg, lack of reminders, lack of transportation), and the COVID-19

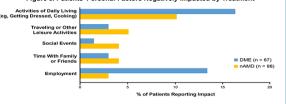
### Figure 1. Anti-VEGF Treatment Barriers Reported by Patients



#### 4. Patient Perspectives of Anti-VEGF Treatment Burden

- Overall, 27% of patients (n = 45) had to travel ≥ 1 hour to attend an appointment and 16% of patients (n = 26) Following treatment, the majority of patients recovered within 1 day; however, 21% (n = 35) needed ≥ 1 day to recove
- Nearly half of the patients (n = 80) reported some level of impairment in their daily activities due to treatment
- Among the working patients (n = 26), 58% (n = 15) reported some level of productivity impairment in the form
- About 31% patients (n = 51) also reported that personal factors were negatively impacted by treatment. Specific types of impacted personal factors are shown in Figure 3

#### Figure 3. Patients' Personal Factors Negatively Impacted by Treatment



DME, diabetic macular edema; nAMD, neovascular age-related macular degeneration; VEGF, vascular endothelial growth factor

### 3. Anti-VEGF Treatment Barriers Reported by Caregivers

### Most caregivers (78.5%; n = 22) reported ≥ 1 barrier that prevented patients from receiving treatment or attending visits

#### 5. Caregiver Perspectives of Anti-VEGF Treatment Burden On average, caregivers spent substantial time providing care to their recipients (mean ± SD, DME: 4 ± 4 hours/day, 5 ± 3 days/week; nAMD: 5 ± 7 hours/day, 5 ± 3 days/week)

- Caregivers supported patients with a diverse array of tasks, including transport to appointments, providing emotional support, and helping with shopping and household chores
- 22% of caregivers of patients with DME (n = 2) and 68% of caregivers of patients with nAMD (n = 13) reported that
  treatment appointments impacted their employment, time with friends and family, and traveling or other leisure
  activities (Table 2)
- Among all working caregivers (n = 9), 44.4% (n = 4) reported being impacted by work absenteeism due to appointments

#### Table 2. Aspects of Treatment Burden Reported by Caregivers

Time Spent Caring for Patients, n (%)		
Attending appointment with the patient	6 (67)	16 (84)
Travel time spent 1–6 hours to and from appointments	5 (56)	11 (58)
Time spent (< 5 hours) helping during patients' recovery from injections	5 (56)	15 (79)
Personal Factors Negatively Impacted by Injections or Examinations, n (%)	DME (n = 9)	nAMD (n = 19)
Employment <sup>a</sup>	1 (11)	3 (16)
Taking care of someone else (eg, child, spouse, parent)	1 (11)	3 (16)
Time with family or friends	0	4 (21)
Social events	0	1 (5)
Traveling or other leisure activities	0	3 (16)
Activities of daily living (eg, getting dressed, cooking)	1 (11)	2 (11)
Other	1 (11)	1 (5)
None of my personal factors are impacted by the care recipient's treatment	6 (67)	9 (47)
Missing	0	1 (5)

### DME, diabetic macular edema; MacTSQ, Macular Disease Treatment Satisfaction Questionnaire; nAMD, neovascular age-related macular degeneration; NEI VFQ-25, National Eye Institute Visual Function Questionnaire-25; RetTSQ, Retinopathy Treatment Satisfaction Questionnaire

7. Caregiver Reaction Assessment Scores

Figure 4. Patient-Reported NEI VFQ-25 Mean Scores

#### The Caregiver Reaction Assessment subscale ranges from 1 to 5, with higher scores representing higher levels of perceived burden, except for the self-esteem subscale, for which the interpretation is reversed

6. Patient-Reported Vision-Related Functioning and Treatment

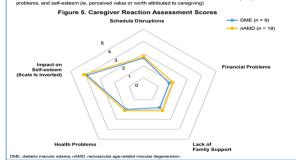
NEI VFQ-25 composite scores (range, 0-100) tended to be moderately high (mean ± SD score, DME: 77.5 ± 24.7;

Both patient groups reported moderately high levels of satisfaction with their current treatment. RetTSQ mean ± SD

nAMD: 77.7 ± 21.6). Mean subscale scores were highest for color vision and lowest for general health (Figure 4

total score was 58.8 ± 14.3 (range, 0–78) and MacTSQ mean ± SD total score was 62.1 ± 8.1 (range, 0–72)

The Caregiver Reaction Assessment scores (Figure 5) showed that caregivers experienced a moderate impact on schedule disruptions, whereas a milder impact was reported for financial problems, lack of family support, health problems, and self-seteem (i.e. perceived value or worth attributed to caregiving)

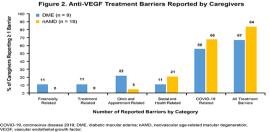


Most barriers were related to COVID-19 pandemic restrictions, particularly with regard to caregivers being unable

Despite being reported by only a minority of caregivers, other barriers included clinic/appointment factors

(eg. distance, difficulty in scheduling appointments, other medical appointments as priority, appointment

duration) and social-/health-related factors (eg, caregiver's availability and care recipient's reduced



#### References

#### Financial Disclosures

- MKA: Speaker: Genentech, Inc., Regeneron; Consultant/Advisor Allergan, Dutch Ophthalmic Research Center, Genentech, Inc., F JL.\* HBL, AP: Employee: ICON plc; Consulting Fees: Roche GCC, BG, VG: Employee: Genentech, Inc.

Study Disclosures

Vision-Specific



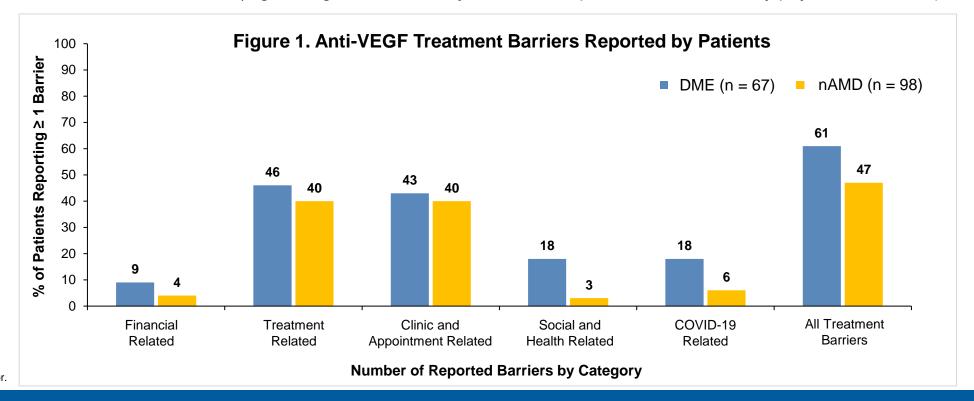
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## Methods

- Between January and August 2021, 67 patients with DME (mean ± SD, age: 65 ± 11 years; VA: 68 ± 22 ETDRS letters) and 98 patients with nAMD (mean ± SD, age: 80 ± 8 years; VA: 61 ± 24 ETDRS letters) treated with anti-VEGF IVT for ≥ 12 months and 9 caregivers of patients with DME and 19 caregivers of patients with nAMD across 9 clinical sites in the United States completed cross-sectional quantitative surveys either online, on paper, or by telephone interview
- The patient survey comprised de novo questions and the following PRO measures:
   NEI VFQ-25, RetTSQ (DME), and MacTSQ (nAMD)
- The caregiver survey comprised questions on caregiver sociodemographic characteristics and relationship with the care recipient, de novo questions on the care recipient's clinical history and treatment experience, de novo questions about experiences and impacts of caregiving, and the Caregiver Reaction Assessment to measure caregiver burden and feelings associated with caregiving

# Barriers to Following Anti-VEGF IVT Management Plan

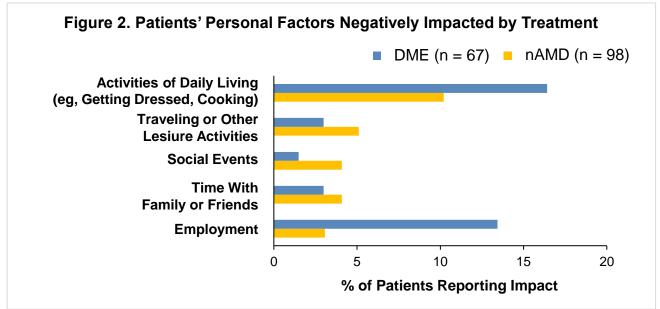
- About two-thirds of patients with DME (n = 41) and half of patients with nAMD (n = 46) reported ≥ 1 barrier to attending injection visits, whereas most caregivers (78.5%; n = 22) reported ≥ 1 barrier that prevented patients from receiving treatment or attending visits (**Figure 1**)
- 12% of patients with DME (n = 8) and 3% of patients with nAMD (n = 3) reported missing ≥ 1 injection visit in the past 12 months
- Clinic and appointment factors and barriers related to the COVID-19 pandemic were commonly reported by both patients and caregivers
- Other patients reported barriers related to treatment (e.g., pain and discomfort or absence of treatment benefit), whereas caregivers reported barriers related to social-/health-related factors (e.g., caregiver's availability and care recipient's reduced mobility/physical limitations)



COVID-19, coronavirus disease 2019; DME, diabetic macular edema; IVT, intravitreal therapy; nAMD, neovascular age-related macular degeneration; VEGF, vascular endothelial growth factor.

# Patient Perspectives of Anti-VEGF Treatment Burden

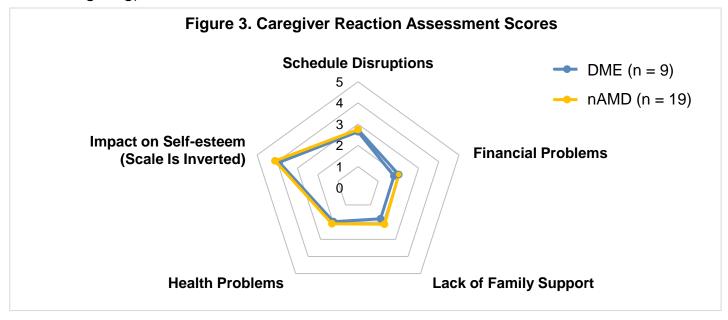
- Overall, 27% of patients (n = 45) had to travel ≥ 1 hour to attend an appointment and 16% of patients (n = 26) reported spending ≥ 1 hour in the waiting area before being seen
- After treatment, the majority of patients recovered within 1 day; however, 21% (n = 35) needed > 1 day to recover
- Nearly half of patients (n = 80) reported some level of impairment in their daily activities due to treatment, whereas among working patients (n = 26), 58% (n = 15) reported some level of productivity impairment in the form of absenteeism
- About 31% of patients (n = 51) also reported that personal factors were negatively impacted by treatment (Figure 2)
- Across the 2 indications, NEI VFQ-25 composite scores tended to be moderately high (mean score, DME: 77.5; nAMD: 77.7). Treatment
  satisfaction among patients with DME (RetTSQ mean total score, 58.8) and nAMD (MacTSQ mean total score, 62.07) was moderately high



DME, diabetic macular edema; MacTSQ, Macular Disease Treatment Satisfaction Questionnaire; nAMD, neovascular age-related macular degeneration; NEI VFQ-25, National Eye Institute Visual Function Questionnaire-25; RetTSQ, Retinopathy Treatment Satisfaction Questionnaire; VEGF, vascular endothelial growth factor.

# Caregiver Perspectives of Anti-VEGF Treatment Burden

- On average, caregivers spent substantial time providing care to their recipients (mean ± SD, DME: 4 ± 4 hours/day, 5 ± 3 days/week;
   nAMD: 5 ± 7 hours/day, 5 ± 3 days/week)
- 22% of caregivers of patients with DME (n = 2) and 68% of caregivers of patients with nAMD (n = 13) reported that treatment appointments impacted their employment, time with friends and family, and traveling or other leisure activities
- Among working caregivers (n = 9), 44.4% (n = 4) reported being impacted by work absenteeism due to appointments
- Caregiver Reaction Assessment scores (**Figure 3**) showed that caregivers experienced a moderate impact on schedule disruptions, whereas a milder impact was reported for financial problems, lack of family support, health problems, and self-esteem (ie, perceived value or worth attributed to caregiving)



## Conclusions

- Patients and caregivers reported impairment of daily activities, barriers, and burden linked to the anti-VEGF IVT management of nAMD and DME, despite the relatively high adherence and treatment satisfaction of patients
- Caregivers devote significant time to caring for their care recipient, with the greatest impact on caregiver schedule disruptions and absenteeism for those still working
- More durable therapies with longer treatment intervals and fewer clinic visits could potentially alleviate the treatment burden and address current barriers experienced by patients and caregivers